

# Impact of parent peer support to parents of a child with a disability, special needs, or chronic health condition: a national cross-sectional survey

A thesis submitted as per requirements of Master Health Science at the University of  
Canterbury

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### **Attestation of Authorship**

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a University or other institution of higher learning, except where due acknowledgment is made in the acknowledgments

Jessamy Gandy

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## **Ethics Approval**

Ethical approval for this study was gained through the Human Ethics Committee at Canterbury University on 02 February 2015 reference number HEC 2014/84. The letter of approval can be found in Appendix A.

## Abbreviations

ASD	Autism Spectrum Disorder
CCS	CCS Disability Action – previously known as Crippled Children’s Society
CDPF	China’s Disabled People Federation
CEO	Chief Executive Officer
FES	The Family Empowerment Scale
GP	General Practitioner
IHC	The New Zealand Society for the Intellectually Handicapped
IHCPA	Intellectually Handicapped Children’s Parents Association
KIPP	Kansas Inventory of Parental Perceptions
MOE	Ministry of Education
MOH	Ministry of Health
MSD	Ministry of Social Development
NASC	Needs Assessment and Service Co-ordination service
NZ	New Zealand
ORS	Ongoing Resourcing Scheme
PAR	Participatory Action Research
PCES	Parent Coping Efficacy Scale
SPS	Social Provisions Scale
Rev.	Reverend
RTLB	Resource Teacher: Learning and Behaviour
UK	United Kingdom
UN	United Nations
USA	United States of America
WHO	World Health Organisation

## Abstract

*Background:* The disability sector in New Zealand has come a long way. There was a time when those with a disability were interred in “mental asylums” alongside prisoners and those who were mentally ill. In the 1930s individuals with an intellectual disability were recognised as a separate population and placed in institutions from the age of five years. Institutionalisation dominated the disability sector in the twentieth century. However, the last institution closed in 2006, ushering in an era of community living. The medical model or deficit based view of disability has been replaced in policy and legislation by the social model; however, the medical model still dominates. Despite these apparent positive changes parents who have a child diagnosed with a disability, special needs, or chronic health condition often have higher rates of stress, depression, and parental separation. Parents are required to navigate through a world of medical terms and eligibility criteria as they try to gain support and access to services. Parent to Parent New Zealand provides support to parents and caregivers of a person diagnosed with a disability, special needs, or a chronic health condition. The main way in which this support is provided is through clients of Parent to Parent being matched with a Support Parent, who is someone who has their own experience of supporting an individual with a disability. Although there has been international research on this supportive relationship, there has been no such research in the New Zealand population to date. Therefore the current study sought to answer three questions: who is accessing Parent to Parent NZ, why and what services are the accessing and finally did those who were paired with a Support Parent find the experience useful?

*Methods:* A national cross-sectional design was employed, utilising an electronically delivered questionnaire via the SurveyMonkey® ([www.surveymonkey.com](http://www.surveymonkey.com)) platform. The questionnaire underwent piloting before implementation. In addition to demographic information, the survey tool used in this study adapted instruments used in previous studies such as the Kansas Inventory of Parent Perceptions (KIPP) and the Parent Coping Efficacy Scale (PCES) to yield quantitative data. Opportunity was given for participants to leave comments which provided support to the quantitative data. Descriptive thematic analysis was used to assess these comments. Participants were recruited through Parent to Parent via their mailing list, electronic media (such as electronic newsletters, Facebook, and Twitter), and their national magazine. There was no restriction on the timeframe in which participants are or were involved with Parent to Parent. The survey was available nationally providing the person had access to the internet. The advertisement placed in the

Parent to Parent media supplied a link to an online survey where participants were asked to complete a 10-15 minute survey. The survey consisted of three sections, totalling 28 questions. The first section collected demographic information, the second section collected information on what services participants have accessed at Parent to Parent and why they accessed those services, the third section looked at the impact of being paired with a Support Parent. Reporting followed best epidemiological practice and was informed by the STROBE guidelines ([www.strobe-statement.org](http://www.strobe-statement.org)), which were used as guidance throughout the study.

*Results:* Of an estimated total population of 10,600 parents involved with Parent to Parent New Zealand, 26 participants accessed the online questionnaire by using a link that was provided on the various advertised mediums. Participants were predominantly New Zealand Europeans from two-parent households. All of the participants were the biological parents of individuals with a disability, special needs, or a chronic health condition. Quantitative and qualitative data was gathered from information provided by the 24 participants who completed sections 1 and 2 of the questionnaire. Further quantitative data was provided by the 19 participants who were matched with a Support Parent at the time they participated in the study. Forty-six percent of contacts with Parent to Parent were seeking information from the organisation. Sixty-seven percent found the information service the most useful service offered by Parent to Parent, surpassing the Support Parent connection at forty-six percent. Overall, participants reported a positive interaction with their Support Parent with sixty-two percent feeling that their Support Parent match worked for them. However, only forty-two percent of the participants gave a positive response to feeling as though their Support Parent gave them someone to talk to about their child's disability. No significant relationships were found between the participants' level of existing support (such as partner or family) and the severity of the disability (all Fisher's exact tests  $p>0.05$ ). A thematic analysis of the comments made by the participants revealed similar themes previously found in other studies.

*Discussion:* Despite many efforts, participation in the survey was disappointing. The diminutive sample size meant statistical power was too small to detect significant differences in the quantitative data and so no firm conclusions could be drawn from the results of this study. Whilst the results of this study drew similar themes to overseas research, due to its sample size it can only be viewed as an exploratory piece of work. Further research is still required to determine whether peer support via organisations such as Parent to Parent is an effective tool to assist parents to feel empowered, less isolated and better able to cope.

## **Chapter 1 – Introduction**

### **1.1 Disability: a New Zealand historical context**

Disability was first mentioned in New Zealand during the mass immigration of British people in the nineteenth century. The 1882 Imbeciles Passengers Act required the ship's master, owner, or charterer to pay a bond of £100 to customs for any passenger who was "lunatic, idiotic, deaf, dumb, blind or infirm" and may require charitable aid (Tennant, 1996, p.7). This was followed by the Immigration Restriction Act of 1899 which took things further, with Section 15 stating that any person who assisted an "idiot or insane person" to land in New Zealand was subject to a penalty and would be charged for the ongoing maintenance of this person (Tennant, 1996, p. 7). At this time there was no differentiation between those with an intellectual disability and those with a mental illness. Asylums and institutions were the norm, with the first public asylum being opened in Karori in 1854 and asylums being established in Otago and Canterbury in 1863, Nelson in 1864, Auckland in 1867, and Westland in 1872 (Tennant, 1996). These were often funded through hospital and charitable aid boards which were the New Zealand equivalent of the charitable boards established under the English Poor Law (Moore & Tennant, 1997). Moore and Tennant (1997) state that the public sector was the biggest contributor of welfare services to those in need in the late nineteenth century. This assertion is in contrast to Tennant (1996), who states that financial support of the disabled was the responsibility of the family, charitable aid or begging.

In 1899 Reverend Mother Mary Joseph Aubert arrived in Wellington from Jerusalem, Whanganui, to set up a home in Buckle Street for the poor and 'incurables' (Munro, 1996). Contrary to Moore and Tennant (1997), Munro states that New Zealand's idea of the deserving poor were only a few widows and that there was scant government financial relief. It was at this time that Rev. Mother Aubert took to the streets of Wellington with her begging prams. Due to their squeaky wheels people would hear coming, allowing them time to gather any leftover food or gifts to give to the nun. With the Buckle Street home full and serving multiple groups in need, the Rev. Mother began rallying support from the Catholic Church, medical practitioners, and other influential people before going to politicians for approval to commission her Home of Compassion in Island Bay, Wellington (Munro, 1996). This was built through personal donations of money, goods, and services, although there were complications. The architect who donated his services was not qualified for such a large build. Furthermore, soon after opening, during a storm water poured into the building and it was

severely damaged (Munro, 1996). However, eventually the home opened and soon housed orphans, those whom could not be cared for by their parent and the incurables. The most commonly noted “incurables” were those with hydrocephalus, spinal bifida, cerebral palsy and Down syndrome (Tennant, 1996). There are also some reports that the Home of Compassion took chronically and terminally ill adults (Moore & Tennant, 1997). At this time the home was neither under the government or classed as a private institution as the Church and the Rev. Mother did not charge a fee for those living in the homes (Munro, 1996). The Rev. Mother and her sisters were at this time running both the Home of Compassion, Buckle St (also referred to as St Joseph’s), a hospice, and an infirmary at St Patrick’s College. The nuns also trained for St John Ambulance and Red Cross Certificates whilst completing all the common tasks associated with the day-to-day running of these establishments (Munro, 1996).

Education of those with a disability was sparse. There was a school for the deaf that was established by the Ministry of Education in Sumner, Christchurch, in 1880 (Moore & Tennant, 1997). In 1907 the Education Amendment Act was passed which required the education of children who were at the time defined as being ‘defective and epileptic’ (Tennant, 1996). This resulted in the opening of the Otekaieke (1907) and Richmond (1916) Schools for ‘feeble minded’ children (Moore & Tennant, 1997). During this time the School Medical Service was founded, with the responsibility of identifying any children who were ‘idiots’, ‘imbeciles’ or ‘feeble minded’ so that they could be sent to an appropriate institution (Stace, 2007). The 1914 Education Act made it a legal requirement for parents, teachers, and the police to report any children who were idiots, imbeciles or feeble-minded to the Department of Education (Stace, 2007).

In 1911, the first legislation that differentiated between someone with a mental illness and someone with a mental disability was introduced (Millen, 1999). The Mental Defectives Act (1911) created seven classes of mental deficiency, and thus those classed as mentally defective, were to be institutionalised from the age of 5 years (Millen, 1999).

Running alongside the government’s legislation was another movement that was gaining momentum elsewhere in the world. The eugenics movement had the potential to influence the very lives of those with disabilities. In Wellington in the early 1900s a meeting was arranged by Member of Parliament Dr William Chapple for medical professionals. This meeting involved guest lecturer Joseph McCabe who was speaking on the topic of eugenics and the “elimination of the unfit from society” (Munro, 1996, p 258). Also attending that evening was the Rev. Mother Aubert who at the

end of the meeting stood in protest to a committee being formed to further the views of eugenics. As part of Rev. Mother Aubert's protest, she referred to her own injury as a 2 year old that had meant years of rehabilitation and a permanent disability. The Rev. Mother is remembered for making the emphatic point "if those views had been in force when I was two years old, I would not be here [...] I was a monster" (Munro, 1996, p. 258). In 1924 a Committee of Inquiry was held into Mental Defectives and Sexual Offenders, and concluded that prompt and effective action was required to prevent the "breeding of the degenerates" that would result in the decline of the strong pioneering stock that originated from Britain (Tennant, 1996). *The Evening Post*, on 2<sup>nd</sup> February, 1925 ran a long article on the Committee's findings, with subheadings such as "seriousness of the evil", "A cancer of the social organism" and "necessity for drastic measures". Public sentiment was being encouraged to support and even put pressure for the creation of mental deficiency colonies (Moore & Tennant, 1997). The eugenics movement saw the expansion of the number of asylums and institutions in New Zealand and in other parts of the world; leading to the imprisonment, sterilisation, and isolation of those classed as mentally defective (Burrell & Trip, 2011).

In 1929, a year after the passing of the Mental Defectives Amendment Act 1928, Templeton Farm opened at a location 13 kilometres away from Christchurch (Hunt 2000). This was the first specialised state institution for 'mental defectives', and there was also a school for children with intellectual disabilities on the site (Lemon, 2001). Shephard (1979, as cited in Lemon, 2001) states the rural nature of Templeton Farm was a means of social exclusion, seen to protect the able-bodied society from the dangers of the disabled. The institution was a working farm, where the male residents could learn skills involved with farming and gardening while the female residents acquired domestic skills (Lemon, 2001). The Templeton Farm model was replicated in Levin, with the opening of the Levin Farm Mental Deficiency Colony on the arrival of 42 young men from Templeton Farm on the 27<sup>th</sup> July 1945 (Hunt, 2000). Following the establishment of the colony in 1945, Levin Farm continued to grow and attract international attention with its training programme, play therapy, speech language therapies, psychopaedic nursing, and school programmes for those that resided there (Hunt, 2000). By 1961 the institute had a waiting list of between 50-60 extreme cases (Hunt, 2000).

Accounts of institutional life vary, with Hunt (2000) describing the early days of the Levin Farm Mental Deficiency Colony in a positive light, especially in reference to the work of Charlie Guy, who was the first Head Attendant. According to Hunt (2000), Guy was adamant that the population of the Levin farm not be ostracised from their local community. Furthermore, Guy believed that the

residents were entitled to have nice things and their own home. By comparison, Millen (1999) quotes a previous resident of the Levin colony who described both herself and others being covered in sores, infected with head lice, wearing clothing from the communal clothing pool, and having no possessions of her own. Both Millen (1996) and Hunt (2000) agree that in the early to mid-twentieth century the birth of a child with a disability brought feelings of shame to many parents. Professionals actively encouraged parents to not take the baby home from hospital and if they did there were few services available to them (Millen, 1996). Most children with a disability were therefore sent to an institution. A proportion of these children had their names changed resulting in some cases of family members only learning of a relative in an institution after the death of the relative's parents (Hunt, 2000).

In 1889, what was possibly the first disability interest group in New Zealand was founded in Auckland. The Association of the Friends of the Blind, was soon joined by Sir Truby King's Plunket in 1907 (Munro, 1996). Alexander Gillies, was a surgeon who had experience with both returned servicemen and polio victims, and a member of Rotary NZ (an international organisation that provides community service). Along with campaigning for a change in attitude towards 'cripples', Gillies was part of the driver for Rotary NZ to set up branches of the Crippled Children's Society in 1935 (Tennant, 1996), an organisation now called CCS Disability Action. The common theme amongst these early groups is that they were founded by professionals, with parents often being left out entirely (Millen, 1996). It was not until Margaret and Hal Anyon considered the educational and life prospects for their son with Down Syndrome with anguish that the first parent-driven group was established in 1949, the Intellectually Handicapped Children's Parents' Association (IHCPA; Millen, 1996). The parents of the IHCPA disliked the term mentally defective and the subclasses of 'idiot', 'imbecile', and 'feeble minded' and thus were the first in New Zealand to use the term intellectually handicapped (Millen, 1996).

The creation of a parent-driven association was the beginning of a way of thinking that ran against institutionalisation and professional opinion for many years. While the IHCPA argued against the colony based institutional system, institutionalisation was still growing (Millen, 1996). In 1953 came the release of the Report of the Consultative Committee on Intellectually Handicapped Children, commonly referred to as the Aitken Report, (Burt, 2013). The Aitken Report summarised that, although the institutions often failed to provide appropriate care for individuals classed as 'idiots', 'imbeciles' and 'feeble minded', there was nothing essentially wrong with institutionalisation (Burt, 2013). The Report encouraged parents to place their 'embarrassing' and 'burdensome' child in an



institution thereby liberating themselves; it also advocated for an expansion of the existing institutions (Burt, 2013). Millen (1996) quotes a parent, Jean Clark, involved in the IHCPA reaction to the release of the Aitken Report, who had expected a very different outcome. There was an expectation of a liberal report recommending community services and small homes, not the expansion of institutions and a recommendation that all children classed as 'idiots', 'imbeciles', and 'feeble minded' be placed in them from the age of five years. This report possibly added motivation for the expansion of the IHCPA, often seen in the beginning as a militant protest group, they began to expand establishing committees throughout New Zealand. The expansion led to the introduction of service provision by the IHCPA (Millen, 1996).

A major breakthrough for the IHCPA occurred in 1954 with the Minister of Health announcing it would assist the IHCPA by subsidising short stay homes for children with an intellectual handicap (Millen, 1996). Although the IHCPA was growing, parents who chose not to go down the path of institutionalisation were still struggling, especially those parents who resided away from the larger cities. When Millen (1996) spoke to parents who had a handicapped child born in 1956, they reported receiving ill-informed advice, few services, and no information.

The 1960s in New Zealand saw the introduction of the Disabled Persons Employment Promotion Act (1960) which, in Stace's (2007) view, created sheltered workshops that had no union coverage or employment rights. Change was also occurring internationally. In 1963, President Kennedy announced a shift from state institutions to smaller community-based care (Lemon, 2001). In the United States of America (USA), United Kingdom (UK), and Australia media coverage on the abuse and neglect of patients in institutions were further raising public and professional concerns with institutionalisation. New Zealander Dr Jack Tizard began a study in the UK in 1957 which took 16 children (matched with controls) aged between four and ten years at the Foundation Hospital (an institution) and placed them in a small residential home (Tizard, 1960). The children had "housemothers" who were responsible for four children. To the best of their ability this was modelled on a home environment with day learning much like a preschool nursery. The Curtis Committee Report (1946) had previously found that orphaned 'normal' children showed backwardness and maladaptive behaviour when placed in institutions. Tizard believed that institutionalisation "warps and stunts the development of already seriously handicapped children" (p. 1042). The results of Tizard's study support this, with children placed in smaller residential homes showing greater gains in functioning, language, and self-sufficiency than their controls (Tizard, 1960).

Whilst the call for deinstitutionalisation was growing internationally, in New Zealand the number of those in institutions had risen from 550 in 1952 to more than 2000 in 1969 (Millen, 1996).

In 1971 the United Nations (UN) released the Declaration on the Rights of Mentally Retarded Persons, followed by the UN Declaration on the Rights of Disabled Persons in 1975 (Bell, Fitzgerald & Legge, 2013). The 1971 Declaration set out 7 points including that if care in an institution is required that this should be in surroundings and other circumstances as close as possible to those of normal life (United Nations Enable, 2003). This was further reiterated in the 1975 UN Declaration of the Rights of Disabled Persons and continued with the right to economic and social security, employment, and the same rights as any other human (United Nations Enable, 2003).

In New Zealand the 1975 Disabled Persons' Community Welfare Act provided loans for modification to vehicles and homes, respite-type care, and increased opportunities for the disabled to be able to access public buildings (Stace, 2007). It also gave provision for the establishment of an advisory committee on services for the disabled, who would provide its recommendations to the Minister of Social Welfare (Tennant, 1996). The 1977 Human Rights Commission Act made it illegal to discriminate on the grounds of sex, marital status, and religious or ethical belief, but failed to include discrimination based on disability (Sullivan, 1991). This omission did not change until the inclusion of disability in the Human Rights Commission Act in 1993 (Sullivan, 1991).

The International Year of Disabled Persons, in 1981, was marked in New Zealand by a telethon which raised public awareness (Tennant, 1996). It was perhaps through this increased awareness that the then Department of Health conducted a review of New Zealand institutions in 1986 (Lemon, 2001). The report that followed found that the environment in many institutions was bare, with an absence of furniture, no toilet facilities, mattresses on the floor, communal living, and the use of punitive measures such as time-out cupboards (Lemon, 2001). Whilst the international scandals had created change as early as the 1960s in the USA, by the late 1980s this journey was only just starting in New Zealand (Lemon, 2001).

Although the New Zealand Royal Commission into Psychopaedic Hospitals in 1972 had recommended a move for those with an intellectual disability from institutions into community-based services, this did not seem forthcoming (Burrell & Trip, 2010). Since its inception, the IHCPA had advocated for community care and viewed the government as unable to keep up with both international deinstitutionalisation trends and demand for community living nationally (Moore &

Tennant, 1997). In 1986 the IHCPA was spending \$43.3 million annually, receiving \$20 million from government sources and was a large national service provider (Moore & Tennant, 1997).

There was slow movement in the inclusion of children with disabilities into mainstream education. There were criticisms around lack of funding, preparation, and support for both the shift to community living and mainstream schooling (Tennant, 1996). This was in part due to the shift going on within government; privatisation was taking place which resulted in performance indicators being set by measurable outputs versus person focused outcomes (Tennant, 1996). Lemon (2001) states that the movement to deinstitutionalisation in the 1980s was primarily due New Zealand's economic decline with the closure of institutions seen as a way to reduce public expenditure.

Lemon (2001) asserts that the National Government used the debt of New Zealand as a reason to do away with the old public health system in the 1990s. Area Health Boards that had previously purchased and provided health services were dis-established and replaced by four Regional Health Authorities to purchase services, with Crown Health Enterprises managing the services (Lemon, 2001). As part of the 1992 government document *Support for Independence for People with Disabilities – A New Deal*, services that were previously state subsidised were to be purchased in a market-inspired contract basis (Tennant, 1996).

In 1996 the Ministry of Education released *Special Education 2000*, which aimed to provide a world-class education provision that provided learning opportunities of equal quality to all students (Fortune, 2013). Special Education was split from the Ministry of Education with schools having to contract and pay for specialist services. It was decided at this time that only 1% of children would require targeted funding under Special Education 2000; although Census data revealed that the actual figure is around 10%, creating a major shortfall that exists to the present day (Stace, 2007).

In 1999, a coalition government between Labour and Alliance saw the medical model of disability disappearing from government policy and being replaced by the social model of disability (Stace, 2007). The medical model had long dominated the field of disability, operating on the basis of what someone could not do, with the problem being with the individual; it is therefore sometimes referred to as the deficit model (Hickey, 2006). Oliver (1990) discussed the importance of definitions and that if a social problem was to be resolved or modified to be acceptable then redefinition of the problem was required. Hickey (2006) summaries Oliver's social model of disability as: separating the impairment from the individual, instead placing the responsibility of access to society on society

itself. Hickey (2006) uses the example given by Finkelstein (1981) that if the world was completely changed to be accessed by wheelchair only it would then be those classed as able-bodied that would be made disabled.

After running a consultation process in 2000 the New Zealand Government released *The New Zealand Disability Strategy – Making a world of difference Whakanui Oranga*, in April 2001. The aim of the disability strategy was to remove barriers which prevent those with a disability from participating fully in society. To achieve this, the disability strategy was to provide a framework that would work across the various agencies, departments, services, policies, and legislation. The disability strategy set out 15 objectives across areas such as rights, education, employment, living situation and creation of a non-disabling society.

In 2002, under the Ministry of Social Development, the Office for Disability Issues was created with a Minister of Disability Issues (Stace, 2007). While still under a Labour coalition the Ministry of Health released the *Pathways to Inclusion* (2001) report and *To Have an 'Ordinary' Life – Kia Whai Oranga 'Noa'* report in 2003 which looked at the social model of disability, inclusion in society, and expectations around employment (Stace, 2007). *Pathways to Inclusion* (2001) focused on the repeal of the Disabled Persons Employment Promotion Act 1960 and provision of genuine employment opportunities for those with a disability. The report *To Have an 'Ordinary' Life – Kia Whai Oranga 'Noa'* looked at whether adults with an intellectual disability had access to the same rights and responsibilities as other New Zealanders and whether they could lead “ordinary” lives. The investigation as part of this report was lead by the National Advisory Committee on Health and Disability. It found that many adults with an intellectual disability were marginalised and had a long way to go to achieve the same rights of citizenship as the rest of the population. They continued by stating the services for this group are stagnating and although there are some exceptions, most are not moving in the direction of the New Zealand disability strategy. The investigation revealed that in the ten years the committee has been providing advice, those with disabilities were the first group whose basic human rights appear to have not been addressed and their aspirations to have an ordinary life not taken seriously. The findings of the report lead to 23 recommendations to both the Minister of Health and the Minister for Disability Issues all with the theme of moving away from generic services that the service user must fit into to a more individualised model of service delivery.

The UN Convention on the Rights of Disabled Persons was signed by New Zealand in 2007 (Stace, 2007). The UN convention sets out its purpose as “to promote, protect and ensure the full and equal

access of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (The United Nations, 2006). It mandates areas such as equality and non-discrimination, awareness raising, accessibility, education and health, among many others across its 50 articles. New Zealand did not need to create any new legislation to implement the convention although a number of minor changes to existing Acts were made to ensure they aligned with the Convention (Disability Rights Promotion International, 2010). The convention requires the signatories to take action to remove barriers preventing those with disabilities from participating in society, this included the right to live in the community (DRPI, 2010). New Zealand’s last institution for those with intellectual disabilities, the Kimberley Centre (previously known as the Levin Farm Mental Deficiency Colony) was closed in 2006 (Bell, Fitzgerald & Legge, 2013), heralding in community living. The convention continued by stating that individuals in New Zealand with disabilities were finding bureaucratic structures that hinder versus help, lack of social participation and well-educated disabled people unable to access employment.

Wiley (2009) interviewed Māori in New Zealand who have a disability along with their caregivers and providers to ascertain their views on their access and use of disability services. The interviews revealed that consumers perceived a need to be extremely proactive to the point of aggressive to gain access to services which in turn often earned them the label of ‘difficult’. Consumers found the number of agencies involved in the sector overwhelming, with very little direction or information offered and that navigation was only possible after decades of experience or support from advocacy organisations. In the same study, the caregivers tended to be more critical than the individuals they were supporting, with the caregivers stating they were very unsatisfied with disability services, and they felt frustrated and disappointed (Wiley, 2009). New parents are finding themselves still isolated by the attitudes bred from the era of institutionalisation, with mothers especially finding their role as one of buffering their child from awareness of these attitudes (Bell, Fitzgerald & Legge, 2013).

## **1.2 Defining and measuring child disability**

Comparing child disability statistics is a surprisingly difficult task. Presently, there is no single globally accepted definition of disability. Kisler and McConachie (2010) state that there are a variety of ways that disability has been defined and measured. They elaborate by stating that age-related disability (conditions such as arthritis) are on the rise and may or may not be included in definitions (Kisler and McConachie, 2010). The World Health Organisation (WHO) states:

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. (WHO, 2016)

Yet while the European Disability Forum also has a social model approach to disability, their definition is far simpler: "Disability is therefore understood as the result of the interaction between the individual's impairment and the barriers created by society (be it social, environmental and attitudinal)" leaving the definition broad and ambiguous (European Disability Forum, nothing about us without us. [http://www.edf-fehp.org/Page\\_Generale.asp?DocID=30471](http://www.edf-fehp.org/Page_Generale.asp?DocID=30471). Accessed on 6 June 2016).

Within New Zealand, there is a similar inconsistency with definitions. For example, Statistics New Zealand (2014) define disability as "an impairment that has a long-term, limiting effect on a person's ability to carry out day-to-day activities. 'Long-term' is defined as six months or longer. 'Limiting effect' means a restriction or lack of ability to perform". By comparison, The New Zealand Disability Strategy uses the definition "Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments [...] Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have" (New Zealand Disability Strategy, 2009). This fits with the social definition of disability that was discussed previously.

According to the 2013 New Zealand Disability Survey, 24% of the New Zealand population was identified as having some form of disability (Statistics New Zealand, 2014). The survey gave a further breakdown indicating that 11% of New Zealanders aged 0-14 years (or 95,000 of the population) have a disability. In Australia, the rate of disability is 12.4% for those aged 0-14 years (Australian Bureau of Statistics, 2012). This is defined as "any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months" (Australian Bureau of Statistics, 2012).

The USA Disability Report utilises a set of six questions to establish disability rather than giving a specific definition. These questions are:

- (i) Hearing Disability (asked of all ages): Is this person deaf or does he/she have serious difficulty hearing?;
- (ii) Visual Disability (asked of all ages): Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?;
- (iii) Cognitive Disability (asked of persons ages 5 or older): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?;
- (iv) Ambulatory Disability (asked of persons ages 5 or older): Does this person have serious difficulty walking or climbing stairs?;
- (v) Self-Care Disability (asked of persons ages 5 or older): Does this person have difficulty dressing or bathing?;
- (vi) Independent Living Disability (asked of persons ages 15 or older): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? (Cornell University, 2013)

People are classed as disabled if they answer yes to one or more of these questions. In the 2013 survey the rates of disability in the USA were, 0.8% for those aged between 0-4 years and 5.3% for those aged between 5-15 years (Cornell University, 2013). The lower rate of disability in the USA compared to other countries is likely due to disability being defined in accordance with the medical or deficit model of disability. Reichman, Corman and Noonan (2008), hypothesise the rate of disability among children in the USA to be somewhere between 6-18%. They state that the reason for the broadness of this range is due to the ambiguous nature of how disability is defined, with terms such as disability and chronic illness being used interchangeably. Reichman et al. (2008) continue their justification on the broadness of this range by stating that the USA does not have a national health database and rather relies on survey based information.

In Great Britain, the Office for National Statistics uses the Life Opportunity Scale which follows the social model of disability and does not equate having an impairment with being disabled. "People may have impairment(s) without being limited in their activities, and therefore they may not consider themselves as disabled" (enquiry number 15243, personal communication, 1 May 2016). The Life Opportunity Scale covers sight, hearing, communicating, mobility, dexterity, pain, health

conditions, learning difficulties, behavioural problems, memory problems and emotional, mental or psychological health conditions (enquiry number 15243, personal communication, 1 May 2016). The Family Resource Survey (2011/2012) found that there were 800,000 British children aged between 0-15 years with a disability (at the time of the survey, the population of Great Britain was 63.7 million and there were 11.6 million individuals with a disability).

Internationally and even domestically there are different definitions of disability. Regardless of how it is measured, those with a disability make up a significant percentage of the population. Although significant in proportion and size, many from this group still feel misunderstood, disadvantaged and isolated.

### **1.3 Parental Perceptions and Coping**

Despite disability being relatively common, however it is measured, when parents are told their child has a disability this typically conflicts with their expectations around how their child should be. How this disclosure occurs can influence the parents' attitudes, values, and expectations surrounding their child (Kerr & McIntosh, 2000) and also their subsequent coping (Sloper & Turner, 1993). Kerr and McIntosh (1998) expand on this by stating that what is said to parents by those in the medical field shortly after the birth of their disabled child can be imprinted on their minds for the rest of their lives.

In a study of parental perceptions, Kerr and McIntosh (2000) found that when their child's disability was disclosed to them, mothers felt shocked, numb, and devastated and had feelings of loss and disappointment. During the remainder of their hospital stay, the mother's feelings often turned to shame, guilt, isolation, and envy. These feelings often continue once the family leaves hospital and parents of children with disabilities are highly likely to suffer from stress, anxiety, and depression (Sloper & Turner, 1993). Sloper (1999) estimates that 7% of mothers and 4% of fathers of severely disabled children suffer from high levels of distress over time. This distress and impaired family functioning can impact negatively on the child and any other children in the household. Furthermore, parental distress may also have a negative impact on the child's cognitive, behavioural and social development.

The stressors associated with having a child with a disability include the ongoing acceptance that the



child has a disability, how this changes the lives of the people around that child, the financial pressures of extra care (one parent may have to give up working), the difficulty of gathering accurate information about the diagnosis, accessing appropriate respite services, and in some cases, ensuring that any siblings are not feeling left out (Ainbinder, et al., 1998). Parental distress may also increase around transitional points in a child's life; for example, when the child starts school, the parents may perceive further discrepancies between their child and other more 'normal' children. This gives weight to the argument that it is not a case of parents one day waking up and accepting the circumstances but that the adaptation to their child's disability is life long, punctuated by milestones that may never be achieved (Santelli, Turnbull, Sergeant, Lerner & Marquis, 1996; Sloper & Turner, 1993).

Reichman, et al. (2008), state that existing studies have found that having a child with a serious health condition increases the likelihood of parental divorce or separation, maternal unemployment, maternal reliance on public assistance and welfare, and a reduction in paternal working hours. Namkung, Song, Greenberg, Mailick, and Floyd (2015) refer to similar existing studies taking the approach that parental separation often happens at differing life stages of the child, with the majority of separations occurring not long after diagnosis. Namkung et al.'s (2015) study took data from the Wisconsin Longitudinal Study, which found that the parents of children with a developmental disability and a smaller family size were at higher risk of divorce. The parents sampled were born in the 1930s; they had married young and a high proportion of the sample identified as being younger cohorts. Namkung et al. (2015) hypothesized that today's families maybe more vulnerable to divorce when the birth of a child with a disability occurs due to societal changes around perception of divorce. Loft (2011) expands on this by considering the protective factors against parental separation stating that parents who have known each other longer, have more economic resources available to them, more years of schooling, are in good health, and have come from a household where their parents were still together are likely to continue with their relationship.

Parents not only have their own experience to come to terms with, they must also account for how other people interact with and respond to their child with a disability. Parents express concern about how others will react to their child (Kerr & McIntosh, 1998). Events that should be enjoyed and eagerly anticipated (such as showing a baby off) become potentially traumatic for the parents of a child with a disability. Furthermore, the parents of a child with a disability may seek to avoid social situations - often compounding feelings of isolation (Kerr & McIntosh, 2000). Singer, Hornby, Park,

Wang, and Xu (2012) discuss previous research that points to parents in the USA and Asian nations can suffer from stigma because of their child's developmental disability. They discuss Goffman (1963, as cited in Singer et al., 2012) who gives the definition of stigma as the perception that a person's identity is damaged and that this impacts other areas of the person's self-image. Goffman (1963) continues by proposing that there is a negative halo effect that causes the families of those with a disability to also be stigmatised. The successes of a child often bring their parent a certain sense of pride; however, when children with a disability do not reach the standards expected by their parents, it can result in a sense of shame and lack of value to the family (Singer et al. 2012). Green (2007) found support for this in her research; expanding on the by stating that maternal experiences of stigma play a substantial role in caregiver burden and the possibility of continuing emotional distress.

However, it is not all negative. Evidence suggests that the majority of families do adapt to having a child with a disability or chronic health condition and even report benefits (Singer et al., 2012). With the changing focus of disability that is occurring worldwide, from a deficit model to the social model, there is an increasing shift in the literature, from a negative focus to one of benefits (Green, 2007). Reichman et al. (2008) touch on these benefits, stating having a disabled child can broaden horizons, increase awareness of inner strength, enhance family cohesion, and encourage community connections. Bayat (2007) expands on this by asserting that parents report a change of their perspective on life and experience increased sensitivity, opportunities to learn, increased confidence, and assertiveness.

#### **1.4 Navigating the System**

Parents in New Zealand and abroad currently have to navigate their way through various government departments and service providers in order to gain access to services. This is not unique to New Zealand, as children with disabilities often require more support and access to financial, therapeutic, and material resources than children with normal needs. Reichman, et al. (2008) discuss the increased needs of American children with a disability and the need for their parents to successfully navigate the idiosyncratic and ever-changing landscape of disability provision in the USA, which often requires parents to be proactive and enterprising. Furthermore, the complexity of American disability system often requires the parents of children with a disability to hire a child-disability lawyer or a consultant to assist with navigating the system.

Depending on their child's age and disability, special needs, or health condition, in 'Western' countries, parents will often interact with multiple healthcare professionals. For example, in New Zealand, the parents of a child with a disability may utilise the services of a general practitioner, a paediatric specialist, a neurologist, specialist medical teams, a behaviour support specialist, an occupational therapist, a speech language therapist, an educational psychologist, a school principal, a teacher aide, and a teacher. Furthermore, the parents of disability service users are often required to interact with a wide variety of government departments. In New Zealand, to gain basic access to funding through the Ministry of Health and the Ministry of Social Development the person must have a diagnosis and be assessed by their local Needs Assessment and Service Co-ordination (NASC) agency. Financial assistance from Work and Income (which is a department of the Ministry of Social Development) could include special grants and support and the child or adult disability allowance. The Ministry of Education in New Zealand offers a variety of services such as special education (comprised of psychologists, occupational therapists, speech language therapists), resource teachers for learning and behaviour (RTLb) and funding systems such as Ongoing Resource Schemes (ORS). When development and progress are occurring satisfactorily for an individual with a disability, for example they are healthy with no major complications in development or behaviour, there may be little need for multiple agencies to be involved with the individual's support. However, when things are not going well the number of agencies involved increases.

There are the day-to-day questions for parents, including: can my child attend the local school?; can we access respite services?; what support groups are available?; what happens after school?; and how do I access residential services? There are a number of agencies and government departments in New Zealand, (such as the aforementioned), and a number of others such as Plunket, Open Home Foundation, Deaf Aotearoa, New Zealand Down Syndrome Association, Autism NZ, Weka, and Parent to Parent NZ, to name just a few. However navigating through these agencies, knowing what help to ask for and where from can be both difficult and stressful for parents. According to Sloper (1998) parents find it a constant battle to find out what services are available, to understand the roles of various agencies, and just who to go to for help.

Ainbinder and colleagues (1998) assert that having social support is crucial for a parents' successful navigation through life with a disabled child. They state that social support is recognised as an effective buffer against the stress and isolation that this population faces. Namkung, et al. (2015) agree that social support is a stress buffer adding that problem-focused coping and positive affect

also help in this parenting role. However, not all parents have someone in their support circle that can provide the social support required. Family members or friends often do not know how they can help, and so withdraw (Namkung et al, 2015). Families that have a child with a disability often have a smaller social network than those that do not (McConkey, Truesdale-Kennedy, Chang, Jarrah & Shukri, 2008). This is where social support organisations like Parent to Parent come in to play. Parent to Parent New Zealand is a nationwide organisation that supports families who have a child with a disability, special needs, or chronic health condition. Based on the Parent to Parent model developed in the USA, Parent to Parent was established in New Zealand in 1983. Parent to Parent offers support groups, Support Parents, and information and will be discussed further in Chapter 2.

A relatively large number of organisations are available to the parents of a child with a disability, special needs, or chronic health condition. A detailed list is provided in Appendix B and at <http://www.kidshealth.org.nz/health-and-disability-support-z>. A comprehensive comparison of these agencies to Parent to Parent New Zealand is not relevant to this discussion. However, Table 1.2 presents a sample of service providers that were selected based on similarities and breadth across health and disability. The majority of the organisations presented in Table 1.2 provide information and education and training. Only Parent to Parent NZ, the Prader-Willi Association, NZ Down Syndrome Association and Autism NZ offer Support Parents. The majority of the organisations target a specific condition or cluster (e.g., IHC and all intellectual disabilities), whereas Parent to Parent NZ is the only organisation that works across disability and health.

Table 1.2. Services provided by other organisations in New Zealand compared to Parent to Parent.

Organisations	Advocacy <sup>1</sup>	Advice	Awareness	Education/ training <sup>2</sup>	Events	Information	Inter-agency cooperation	Meetings	Newsletters/ magazines	Residential services	Support Parent	Life skills and living assistance <sup>3</sup>
Autism NZ Inc	X	X	X	X		X	X		X		X	
Blind Foundation	X	X		X		X			X			X
CCS Disability Action			X	X			X					X
Child Cancer Foundation	X			X		X		X	X			
Deaf Aotearoa	X	X		X	X	X			X			X
NZ Down Syndrome Association	X				X	X			X		X	
IHC	X			X		X		X		X		X
Kidney Kids NZ				X	X	X			X			
Parent to Parent				X		X		X			X	
Prader-Willi Association	X			X	X	X	X			X	X	
SPELD NZ				X		X						

<sup>1</sup> Advocacy - representing a person with special needs in liaison with other organisations.

<sup>2</sup> Education/training - for parents, caregivers and professionals who support the person, includes providing resources for learning.

<sup>3</sup> Life skills and living assistance - is supporting person in life areas such as employment and within the person's home.

Although there has been a shift from the medical to social model in New Zealand's view of disability, access to services still require a medical diagnosis. The way in which Parent to Parent provides support and information to parents helps them negotiate their way through the health and disability sector. A more detailed discussion of Parent to Parent will be presented in Chapter 2. Parents in New Zealand have anecdotally spoken to Parent to Parent about how useful the access to information and support has been, but to date no evaluation of this has been undertaken.

## 1.5 Purpose of study

The only information that exists on Parent to Parent New Zealand currently is that produced as part of Parent to Parent's own social audit. As far back as the late 1990s it has been noted that there is a body of anecdotal evidence that supports the value of the peer-support relationship, but that systematic evaluation is lacking (Ainbinder et al, 1998). Parent to Parent services across the Pacific Rim are discussed in a review of these services by Singer and colleagues (2012). Although anecdotal evidence suggests that Parent to Parent New Zealand is a valued service, there has been no published research on the effectiveness of the support the organisation offers. The New Zealand

population is a multicultural, diverse society. This diversity is discussed in The Ministry of Social Development's briefing paper *New Zealand Families Today* (2004). The family unit has changed in the course of a generation to include couples with children, sole parents, parents who do not live with their children but are still involved, same-sex couples (some with children), and many family members who have ties of support across households and generations. There are also cultural differences with Māori families tending to have children at younger ages and more children than Pākehā (New Zealand European) families; there is a greater proportion of sole-parent Māori families (although many of them live with other family members); and grandparents and other whānau are more closely involved in Māori children's upbringing than Pākehā grandparents and family members. The same report states that there are different patterns for New Zealand European, Pacific, and Asian families (Ministry of Social Development, 2004). McConkey, et al. (2008) compared the impact of having a child with an intellectual disability on mothers from Irish, Taiwanese, and Jordanian cultures. Whilst they found that all mothers experienced some level of poorer mental health, increased levels of child-related stress and poorer family functioning, these were reported at differing levels across the cultures. As well as New Zealand's unique cultural makeup, the population of New Zealand is widespread, with 72 percent living in an urban area, 11 percent living in an independent area (urban areas away from the main centres), and 14 percent living rurally ([http://www.stats.govt.nz/browse\\_for\\_stats/population/Migration/internal-migration/mobility-urban-rural-areas.aspx](http://www.stats.govt.nz/browse_for_stats/population/Migration/internal-migration/mobility-urban-rural-areas.aspx), accessed on 3 June 2016). Rural areas often mean travel to tertiary hospitals and poorer access to general practitioners (GP). Brabyn and Barnett (2004) state that access to appropriate health services in rural areas is an ongoing concern in New Zealand. These areas often feature high levels of deprivation making travel to seek medical assistance difficult.

Therefore knowing that New Zealand has cultural differences and a contrast between urban and rural populations, there is a need to look at the specific impact of Parent to Parent in the New Zealand population. The expected outcomes of the current study is to look at the New Zealand Parent to Parent population, and the impact made by having contact with a Support Parent through Parent to Parent in today's world. While Parent to Parent has previously completed social audit's where a percentage of the Parent to Parent population was able to partake, this study is the first to welcome responses from every parent involved in Parent to Parent nationally. It is acknowledged from the onset that this is a small exploratory piece of work; however, it is hoped that this information will be useful for Parent to Parent and will allow direction for further research.

## **1.6 Structure of this thesis**

Chapter 2 gives a detailed exposition of Parent to Parent both in the USA and New Zealand, with comparisons drawn between the two. Contact was made with Parent to Parent in Scotland and Australia and the information provided by them will briefly be discussed. The chapter continues by detailing and discussing Parent to Parent New Zealand's principles, history, evolution and how it sits within the health environment. The current status of Parent to Parent in New Zealand will be examined from an organisation, wider public, parent, and funding perspective. Operational details of who Parent to Parent targets, how they are targeted, along with the aspirations of the programme will be discussed. Finally previous studies looking to evaluate the success of Parent to Parent will be described, followed by the specific research questions of the current study.

Chapter 3 gives information on the processes behind the study. This includes the creation of the questionnaire which considered scales and measures used in previous studies. The questionnaire also involved liaising with Parent to Parent to ensure information gained would also be useful to the organisation. A pilot of the study was run accessing the knowledge of five individuals who worked in or had knowledge of the disability sector before the study link went live using a web-based survey medium. Liaison between the author (JG) and the communications manager at Parent to Parent (this role had turnover of 3 staff in the time of the study) was vital for the recruitment of participants via Parent to Parent's networks and social media. The questionnaire provided space for participants to leave open ended comments, these were analysed by comparing to the themes that had emerged in previous studies.

Chapter 4 presents all the analysis done on the information garnered from the questionnaire, and summarise this information. The comments made by participants in the questionnaire are presented in tables and the themes from these comments are reported for further discussion in chapter 5.

Finally, Chapter 5 presents the discussion of findings, considers how the comments made by parents in the current study relate to findings in previous studies, presents the important strengths and limitations of this research, gives the implications of this research, provides ideas for future research, and ends with an overall summary.

## Chapter 2 – Literature review

### 2.1 History of Parent to Parent in the United States of America and New Zealand

The first Parent to Parent Program was started in 1971 under the name the Pilot Parents Program (Santelli, Turnbull, Marquis, & Lerner, 2000). It was started in Omaha, Nebraska, by Fran Porter, a young mother with a child diagnosed with Down Syndrome. Porter worked closely with social worker Shirley Dean to create a program for parents of children with disabilities, where they could share information and emotional support through one-to-one matching with a support parent. A federal grant was received to train and replicate the model in other areas (Parent to Parent USA, 2013). The model spread throughout the USA, however it was fragmented with multiple programs being set up without an overseeing branch or person (Santelli et al., 2000). A survey conducted by the Beach Centre on Families and Disability (based at the University of Kansas) in 1988 discovered that there were hundreds of Pilot Parent Programs throughout the USA that varied from supporting a few parents to several hundred. Regardless of size, all of these programs offered emotional and informational support through a one-to-one match with a Veteran Parent (an individual who had 'lived experience' and had undergone training to provide support to new parents; Santelli et al., 2000). In 2001, *The Parent to Parent Handbook* was published by Brookes Publishing Company. In 2002, funding from the Robert Wood Johnson Foundation was secured to strengthen and coordinate national efforts to ensure access to community-based support for families throughout the USA. This led to an amalgamation of the organisations under the official umbrella of: Parent to Parent of the United States (Parent to Parent USA, 2013).

In 1982, during a special education conference in Perth, a presentation was given regarding Parent to Parent support in Australia (Hornby, Murray, & Jones, 1987). Attending this conference was Garry Hornby, who subsequently met with colleagues Ray Murray and Robin Jones on his return to Auckland. Hornby, Murray, and Jones then met with representatives from Auckland-based disability providers and a number of parents of children with disabilities. Using materials donated from the Perth conference and Parent to Parent Australia this group established Parent to Parent New Zealand in Auckland in 1983 (Hornby et al., 1987).

When the New Zealand branch of Parent to Parent was established there were two key differences from the Parent to Parent services seen in other parts of the world. Firstly, parents of children with a wide range of impairments were included, instead of the traditional intellectual impairments only.



Secondly, when creating the training programme for parents who would become the Support Parents, basic listening and counselling skills were included, as well as how to advocate for those with disabilities. Anne Wilkinson, CEO of Parent to Parent NZ, describes why these differences were included:

With Ray and Garry's 'training' background they suggested to the group that the training should include basic listening skills to ensure the Support Parents were prepared and enabled to provide support and of course to ensure that the person receiving the support has the best possible experience. This would (and has continued) to make the connection through Parent to Parent different from meeting up and sharing with someone parents might meet at e.g. a support group meeting who are experiencing their own grief and are also looking for support – rather than being focused on giving it. The support that parents are looking for is mostly around managing the emotions of their 'grief' which they rarely identify as grief, and so training Support Parents on how best to do this is critical if we are wanting to assist. Ray, Garry and Linda wrote a training course which was delivered to many parents in the Auckland region and was used by Parent to Parent until 2000 when I put together a specific Parent to Parent training course. When Shirley Wass was invited to present on our model at the Parent to Parent international conference in the States, a few years after we established, many of the groups adopted the addition of listening skills into their training and we now share resources with some of these groups.

It was decided from the outset that Parent to Parent in New Zealand would include all disabilities and health impairments – mostly because of our small population and wanting to be totally inclusive. Also, despite the condition parents experience the same emotions and so are well able to support each other even if the conditions are not the same. This all started at the time New Zealand was on its journey of closing the institutions and so children with both intellectual and physical disabilities were able to stay with their families. (A. Wilkinson, personal communication, 15 May 2016)

At the time of Parent to Parent's establishment in Auckland, New Zealand, the traditional facilities for those with a disability were spread throughout the city. Due to the distance between the facilities, there was little contact or co-ordination between them (Hornby et al., 1987). By setting up Parent to Parent to include a wide range of disabilities it was hoped the scheme would "cut across the traditional demarcation lines between handicapping conditions" (Hornby et al., 1987, p. 278).

Educational Psychologists and those working within government psychological services provided training to Support Parents, creating a parent-professional partnership. With the support of a group of parents that were known to Hornby, Murray, and Jones a pilot training course for Support Parents was created (Bell, Fitzgerald, & Legge, 2013). Feedback from this initial parent group encouraged the ongoing inclusion of a wide range of disabilities and a slightly revised training course. The training course consisted of eight 2-hour sessions that focused on personal sharing of parental experience and the process of parental adaption to the disability. Of the eight, four sessions were dedicated to discussions and role play around basic counselling skills (such as active listening) and the final two sessions were on advocacy and referral sources. Parent to Parent had its origins as a telephone service in Auckland, and now is nationwide providing a range of supports that continue to evolve with technology, for example the use of Skype for meetings.

## **2.2 Parent to Parent New Zealand's features compared with other Parent to Parent organisations**

There is no international overseer or branch of Parent to Parent nor is there an international copyright on the name Parent to Parent. However, as Parent to Parent NZ had evolved from the model based in the USA, the author wanted to compare services offered by different Parent to Parent organisations. To compare other Parent to Parent organisations the author made contact with Parent to Parent Australia and Parent to Parent Scotland as they clearly identified themselves as Parent to Parent and were able to be contacted. In Singer et al. (2012) Parent to Parent China and Korea were discussed, attempts to find further information on and contact these organisations was unsuccessful. Information on these Parent to Parent organisations is discussed but only from the standpoint of what is reported by Singer et al. (2012). Carolyn Jury (Support Parent Co-ordinator) at Parent to Parent New Zealand was contacted and advised that Parent to Parent New Zealand had international connections but these were not with other Parent to Parent organisations (with the exception being the USA), instead they make contact with an organisation that is for a specific rare condition even though these organisations do not always offer Support Parents (C Jury, Personal Communication, 13 December 2015). Further searches for organisations under the title of "Parent to Parent" yielded no results. Requests were made for any available literature from Parent to Parent in Australia and Scotland, and while those spoken to were able to provide organisational documents, they were unaware of any research or further literature on or related to their Parent to Parent organisations.

### 2.2.1 Parent to Parent New Zealand's objective / vision

Parent to Parent's mission is empowering families and whānau of people with disabilities and health impairments through support and information (Parent to Parent, 2011). Their statement of purpose stipulates:

The purpose of Parent to Parent New Zealand is to empower parents, caregivers and whanau who have children and family members with disabilities, health impairments or special needs through support and provision of information. Parents will feel supported and informed as a result of their contact with Parent to Parent. Parent to Parent will do this in a cost effective and equitable manner.

Parent to Parent New Zealand supports thousands of families every year by:

- Providing information, advice and support
- Linking families locally, nationally and internationally with other families of children affected by the same condition, enabling a mutual support network to be established
- Training Support Parent in the skills necessary to support other parents
- Linking families with trained Support Parent who provide experiences and practical support and information
- Providing parents and family members with information regarding local, national and international support groups
- Responding to requests for information and advice about issues affecting families of children with special needs
- Providing specific support to young people who have brothers and sisters with special needs through the SibSupportNZ programme
- Providing information to the health, social care, and education professions which support people with disabilities/special needs
- Providing a specialised advice and information service through Altogether Autism"

(Parent to Parent, 2005)

Anne Wilkinson explains how the above goals are operationalised and evaluated in a personal communication. Information is provided by making a request, this can be for information on specific conditions, other support groups or, this could be about a specific issue e.g. how to get funding or

educational issues. Information can also be provided at a local level by the coordinators or through organised presentations. Advice can occur on many levels, through the one-to-one relationship with a Support Parent, the person's local coordinator or, through contact with a professional arranged by Parent to Parent. Support is most often provided through the one-to-one nature of the Support Parent relationship. However, support can also come from participation in group activities such as coffee groups or, locally organised training activities (for example, the personal support course). Families are linked based off similarities, with pairings made locally, nationally or internationally. To achieve this Parent to Parent NZ has a relationship with Parent to Parent and 'Mums' in the USA and 'Contact a family' in the UK. Training of Support Parents occurs through Parent to Parent NZ's Support Parent training course. Parent to Parent NZ has had feedback from other organisations and groups (e.g. the Down Syndrome coffee group get to together) that the Support Parent course has a flow on impact when a Support Parent attends the group as they can provide information and support in these more informal settings.

There are multiple ways in which feedback is received for the information provision and Support Parent match. Anyone who is connected with a Support Parent is asked for feedback. This often occurs through a phone call, wherein the parent is asked about the appropriateness of the match, how they found the process, the time it took and if there is anything else they require support with. Feedback is also sought from the Support Parent, who is asked how they felt the contact with the parent seeking support went. If the request for support came via an agency or organisation, Parent to Parent will contact the agency to ask for feedback also. The information service will often post out hard copies of the information requested, and with this is a feedback form and there may be follow up by phone call also.

Support for young people who have brothers and sisters with special needs is provided through the SibSupportNZ® programme which runs camps (SibCamps) and workshops (SibShops). Feedback is gained at the end of these events. The children attending fill out an evaluation before leaving, they then take home an evaluation for their parent or caregiver to complete and send back. This means that Parent to Parent are able to gain feedback from all of the children who attend, although not all the parents send back the feedback forms. The camp leaders (who are volunteers) and the camp parents are asked for feedback on how the workshop or camp went, and to reflect on their performance. The facilitators of the workshops and camp also compile a report.

Parent to Parent has historically provided training to professionals e.g. for medical, education and social services. This often would take the form of awareness, where Parent to Parent would organise

parents to come and share their experiences. Until approximately six years ago Parent to Parent in the Waikato worked with the Medical School to develop and deliver aspects of the Trainee Intern Programme. This would involve all the students who were in their fifth year of training spending a day with a family who were caring for their child with special needs. Unfortunately this had to stop when the interns training programme was added to and there was not enough time available for this to continue. The training of professionals was identified as important in Parent to Parent's three year business plan (2015-2018), as it enables better interactions with families and individuals with a disability, and provides some income for the organisation. Information for the health and education sectors occurs through Parent to Parents involvement in Government working and reference groups. Parent to Parent is involved through parent representatives in the Disability Action Plan. Altogether Autism provides information specifically around those with Autism and has a professional expert group, who provide information through a variety of mediums and have the expertise to be able to respond to complex situations or academic requests. The professional expert group ensures that all information provided is evidence based best practice. Altogether Autism also provides a training programme for professionals, such as teachers and support workers (Personal communication, Wilkinson A, 30 May 2016).

#### 2.2.2 Parent to Parent – Australia, Queensland

On 11 December 2015 the author contacted Parent to Parent Queensland Australia, and spoke with Karen Rollason, Parent Co-ordinator. Their website was in the stages of upgrade, so Rollason kindly posted one of their information packs which included the following information. Their mission statement is "Families influencing society to recognise people with a disability as valued contributing citizens" (Parent to Parent Charter, who we are fact sheet, nd.). Parent to Parent Assoc Qld Inc is based in the state of Queensland Australia, it is a non-government, not-for-profit organisation, funded by Department of Communities-Disability Services to provide support services. They were established in 1998 by a small group of parents with funding assistance from disability services (Parent to Parent Queensland, 2016). Their regional centres are based across Queensland that support people through offering peer support, skill enhancement opportunities, person centred planning, and networking.

### 2.2.3 Parent to Parent - China

In Singer et al., (2012) parent supports in China are discussed, these are offered through four different models, three of which are discussed in the article. The first is registered parent support organisations under the China's Disabled People Federation (CDPF). The CDPF was established in 1988 with the mission "to promote the full participation of persons with disabilities in society on an equal basis with others, ensure that persons with disabilities share in the material and cultural achievements of society, as well as foster humanitarianism in society" (China Disabled Persons' Federation, 2008). Second, 1978 saw the beginning of the period of "Reform and Opening (*gaige kaifang*)" which involved, amongst others, educational reform and the development of special education (McCabe, 2008). These special schools organise parent schools to run training by professionals for parents (Singer et al., 2012). Finally the emergence of Parent to Parent organisations grew out of dissatisfaction for existing supports in China (Singer et al., 2012). Parents have created a website to share information and experiences. McCabe (2008) conducted one of the limited studies into parent to parent support in China, this is unlike the Parent to Parent organisations of New Zealand and the USA. McCabe's (2008) study looked at the second type of support discussed above, where parents of children with Autism attended one of two short term (3 month) intervention programmes. Parents were in classes with other parents and supported each other's learning, so whilst not fashioned in the same way as other Parent to Parent programmes, similar themes emerged such as the sharing and learning from each other and supporting and accepting each other. Also discussed were the high rates of stigma and shame in Chinese society around disability, with the common belief being that disability is caused by the family (most often the mother) doing something wrong. However, McCabe (2008) concluded that the support offered by the intervention programmes were essential for parental support.

### 2.2.4 Parent to Parent – Korea

Parent to Parent Korea is offered at the community and school level, however there is no nationwide initiative. Parent to Parent support was previously the only support for parents prior to the introduction of a national special education system under the Special Education Act for Individuals with Disabilities in 2008 (Singer, et al. 2012). Parent to Parent in Korea is organised by special education professionals who invite parents to participate in a program and organise meetings (Singer et al., 2012). The professionals also match parents with support parents running on the premise of the volunteer parent support relationship (Singer et al., 2012). Since 2005 there have

been two studies on Parent to Parent programs, however, the author was unable to source these articles having gone as far as contacting the Korean embassy for assistance. The articles authored by Jeon (2005) and Jeon and Park (2005) are summarised in Singer et al., (2012), with their findings suggesting that Parent to Parent programs enhance the quality of life of families who have children with disabilities through practical and specific support. The article notes that modern Korean culture is a very private one, where there is a reluctance to share personal problems, even with family, and therefore often Parent to Parent supports families in a group setting before pairing them with their support parent.

#### 2.2.4 Parent to Parent - Scotland

Debra Ritchie, Administration and Finance Manager, from Parent to Parent Scotland replied to the request for information by email on 7 December 2015, she attached a document that was not found in the same format on the website, the following information has come from that document and the full document is attached in Appendix C. In 1988, a conference was held in Ninewells Hospital in Dundee, Scotland, for parents of young children with disabilities, a gap in services from birth to school age was identified and Parent to Parent was created. Originally the Scottish Parent to Parent service was staffed by trained volunteer parents; however, in 2000 the organisation began to hire paid “Support Workers” to provide intensive support. There are now 13 Support Workers and 3 Young Persons’ Support Workers supporting approximately 800 families. This is different to most other Parent to Parent programs that use volunteer peer support parents. They provide support whilst the child is in hospital especially in units such as neonatal intensive care. They also provide one-to-one support, behaviour support, advocacy, and group support. Volunteers do still provide support but this is often after the intensive support from the Support Worker. In her correspondence Ritchie states:

The Support Worker is not required to have a child with a disability or health condition, the person specification looks for someone who is empathetic and understands the issues around parenting a child with a disability and this often attracts parents. We do not look for specific qualifications, rather experience and a warm personality. At present of the 13 support workers we employ 7 have personal experience of caring for a child with a disability or health problem and two are parents whose child has died due to their illness. We do find they bring something extra to the job and the parents they support feel their worker truly understands how they feel.

(D Ritchie, personal communication, 7 December 2015)

In a subsequent email Ritchie advised that they do not have a mission statement but informally their aim is to support parents of children with additional needs and a service that is quite flexible to suit the needs of these families (D Ritchie, personal communication, 6 June 2016).

#### 2.2.5 Parent to Parent – United States of America

As discussed above, Parent to Parent in the USA started off as the pilot parents program in the 1970s and spread throughout the USA as small organisations supporting various numbers of parents (Santelli et al., 2000). In 2003 there was the amalgamation of the organisations under the official umbrella of: Parent to Parent of the United States (Parent to Parent USA, 2013). In its current form Parent to Parent USA states that “For over 36 years Parent to Parent programs across the country have been providing emotional and informational support to families of children who have special needs most notably by matching parents seeking support with an experienced, trained 'Support Parent'” (Parent to Parent USA, 2013). In most branches the service is offered across multi disability, health condition, mental health or behavioural needs (Parent to Parent USA, 2013).

When comparing the Parent to Parent organisations directly in Table 2.1, majority of Parent to Parent groups discussed provide 1:1 peer support. In Scotland this is often after intensive support by a paid support worker, while information from China suggests that they run intense interventions run by professionals on site versus the model seen by other Parent to Parent organisations. While none of the organisations are run solely by volunteers in New Zealand, the USA and Australia volunteers are discussed more in the Parent to Parent material available such as websites. Broader support than just the peer support is offered by support groups in Scotland and New Zealand. Parent to Parent NZ is the only organisation that provides support to siblings (both as children and adults).



Table 2.1 Comparison of services provided by international Parent to Parent organisations compared with New Zealand.

	1:1 peer support	1:1 paid staff support	Info	advocacy	Sibling support	Support Groups	Behaviour management	Courses/ intensive intervention	Skill enhancement	Peer support using person centred planning	Professional lead	Not-for-profit
Australia	X		X						X	X		X
China								X			X	
Korea	X										X	
NZ	X		X	X	X	X						X
Scotland	X	X	X	X		X	X	X				
USA	X											X

## 2.3 Current Status of Parent to Parent New Zealand

Parent to Parent New Zealand is a nationwide not-for-profit organisation that supports families with children that have a disability. It operates via 11 regional groups reporting back to the national office based in Hamilton. The regional groups provide information and resources, Support Parent matching, and training for Support Parents. Depending on demand, the regional groups facilitate morning coffee meetings for parents and provide family or parent weekends and information evenings. Regional groups are responsible for their own funding, and pay a fee to the national body for the work that it does on their behalf. The regional groups are based in Whangarei, Auckland, Hamilton, Tauranga, Rotorua, Palmerston North, Wellington, Nelson, Christchurch, Dunedin, and Invercargill (Parent to Parent NZ, 2011).

Parent to Parent NZ's national office supports families based in areas where the regional groups do not operate. The national office also provides support to the regional groups to match a parent with a Support Parent when the condition is rare and may mean finding a Support Parent in another part of New Zealand or internationally. Based at the National Office are 15 staff, including the Chief Executive Officer, National Manager, Programme Administrator, Altogether Autism National Manager and Psychologist, Matching and Information Staff, and Administration Support. The

National office runs both the Parent to Parent webpage and their toll-free line, enabling the support and provision of information on approximately 3,500 different conditions covered by the organisation. The national office is responsible for SibSupportNZ®, a nationwide programme that is designed to offer support to young people that have a brother or sister with a disability. In 1999, a Ministry of Health contract was awarded to Parent to Parent to deliver the Family/Whanau Carer Support Programme, which is a weekend away for parents to attend workshops that provide information and support around grief, communication, and stress. This also allows parents to build their own networks and supports with other attending parents. The National Office also has a relationship with other organisations within New Zealand and internationally and health professionals in the health and disability sector (Parent to Parent NZ, 2011).

As the governing body of Parent to Parent NZ, the national board oversees the organisation's wider issues including the setting and monitoring of the strategic direction and establishing and monitoring of policies. At annual general meetings every two years, elections are held by the regional groups for the National Board positions, which are made up of five members and a President.

As of November 2015 there are approximately 627 Support Parents with Parent to Parent NZ, with the role of the Support Parent being a voluntary one (C Jury, personal communication, 1 December 2015). To become a Support Parent those interested must complete the training course that is offered by Parent to Parent NZ (Parent to Parent, 2011).

The last social audit completed by Parent to Parent NZ ran from 1 July 2004 to 2 June 2005. In that time 676 parents contacted Parent to Parent requesting to be matched with a Support Parent, 961 parents made contact seeking information, 20 children attended a SibSupportNZ®, and 46 parents attended the Family/Whanau Carer Support Programme. Referrals to Parent to Parent were looked at during this time and it was found that there were a variety of ways a referral to Parent to Parent occurred. The most common referrals came from 'hospital', followed by teachers/school, other support groups, the Parent to Parent brochure, community networks, friends, phonebook, and Plunket (Parent to Parent NZ, 2005). A comparison of this information to how referrals occurred in 2015 is presented Table 2.2. The social audit resulted in the development of an action plan to address some of the points raised in the audit. Due to difficulties with Support Parent matches working, a goal was created to ensure that when seeking a Support Parent match, parents were advised that matches were based on similarities (including demographic, or specific issue e.g. toilet training) and that Parent to Parent NZ was not always able to match exactly on the condition of the

child. Due to those seeking support not always receiving the support expected, follow up calls were to be actioned to ensure the Support Parent had made contact. It was also noted that diversity of Support Parents was lacking and therefore, an effort was made to increase recruitment of Support Parents from diverse backgrounds.

In 2015, Parent to Parent NZ commissioned research into their SibSupportNZ® camps and workshops. Previous research on Parent to Parent internationally has found that perceived sameness is vital to the relationship between the parent seeking support and the Support Parent (Ainbinder et al., 1998). Similarly, feedback from the 2015 SibSupportNZ® research suggested that the facilitators of the sibling programmes being siblings themselves was a critical component to its success. It was reported that those who attended the camps had improved relationships with their parents and disabled siblings, better communication with their parents and increased confidence, and self-esteem. Parents of the siblings reported that they liked that it put focus on the sibling for the weekend instead of having to plan around the child with the disability or health condition (Boswell & Appleton-Dyer, 2015).

## **2.4 Who Parent to Parent New Zealand targets**

In the early 1990s parents were targeted through the Canmer Maternity packs. These were at the time given to over 56,000 new parents throughout New Zealand whilst they were in hospital for the birth of their child. The pack contained a brochure on Parent to Parent NZ. The Canmer Maternity packs no longer exist; however, Parent to Parent brochures are still sent out to service providers such as Plunket, preschools, and the Citizens Advice Bureau (R Smith, personal communication, 27 February 2016). As Parent to Parent NZ has grown in size, awareness of the organisation has spread. Increasingly more people are being referred to Parent to Parent with the total parents involved reaching over 10,600 in 2015 (J Eastwood, personal communication, 10 April 2016). Parent to Parent collect data on where parents requesting information found out about the organisation. Table 2.2 gives information on where those parents who responded to the 2005 social audit heard about Parent to Parent, compared to those who contacted Parent to Parent in 2015. The information provided for 2015 came from Parent to Parent's database as it is collected at first contact. The organisations in Table 2.2 have been grouped according to type of service they provide (e.g. health or education) due to the large number of organisations; the full list of service providers is available in Appendix D.

Table 2.2 – How parents accessed Parent to Parent in 2005 compared to 2015.

	2005	2015
	n (%)	n (%)
Brochure	5 (15.2)	5 (0.3)
Community Networks	2 (6.1)	0 (0.0)
Friend	2 (6.1)	57 (3.3)
Hospital	9 (27.3)	46 (2.7)
Other Support Group	5 (15.2)	8 (0.5)
Plunket	1 (3.0)	7 (0.4)
Phone book	1 (3.0)	0 (0.0)
Teacher/School	8 (24.2)	7 (0.4)
Altogether Autism		307 (17.9)
Education Services – excl teacher/school		16 (0.9)
Family		13 (0.8)
Health Services – excl hospital		317 (18.5)
Not specified		448 (26.1)
Other Disability Services		171 (10.0)
Other/not enough info		61 (3.6)
Parent to Parent materials or staff – excl brochure		112 (6.5)
Social Media/internet		56 (3.3)
Word of mouth		84 (4.9)

Comparing how people accessed Parent to Parent in 2005 to 2015 is difficult, in that the 2005 data comes from a smaller sample size from the social audit, whereas the 2015 data is collected at time of contact and represents all contacts for 2015, totalling 1,715. In 2015, no-one used the phonebook as a source of contact; however, 3.3 percent of contacts were due to finding Parent to Parent on social media or through their website, which indicates how people access information in the present day. More health services referred parents on to Parent to Parent than education services, while not completely surprising that this occurred it is interesting to note the large difference in this number. This is likely to be as health providers are the organisations providing diagnosis of the child and at the time of diagnosis families are often referred to Parent to Parent.

## **2.5 Previous Research and Success of Parent to Parent Internationally and in New Zealand**

In the 1990s a sizeable body of research on Parent to Parent came out of the USA. The following two decades saw little research being undertaken on the services Parent to Parent provide. However, recently there has been an increase in research on Parent to Parent globally. The main studies from the 1990s will be discussed below.

Santelli, Turnbull, Marquis, and Lerner (1995) conducted their research when family-centered services were an emerging trend in the USA. The Beach Centre on Families and Disability at the University of Kansas conducted a national survey of Parent to Parent programmes and it was through this survey that the questionnaires for Santelli et al.'s (1995) study were distributed. The questionnaires targeted both the referred parent and the Veteran Parent (Support Parent) and used closed and open questions to gain information on the following five areas: (1) the demographic details of the families accessing Parent to Parent, (2) the reasons why families accessed Parent to Parent services, (3) how the supported families found the match with their Veteran Parent, (4) the type of support the families received (e.g., emotional support), and (5) any other services or programs accessed on top of the Veteran Parent match. As well as the aforementioned question, the Veteran Parent questionnaire contained additional questions about the training they had received. Overall, 704 referred parent questionnaires and 629 Veteran Parent questionnaires were sent out, the return rates of these were 240 (34%) and 330 (52%), respectively, and this response was assisted by sending out two reminders via a mailed postcard. The study found that the majority of parents involved in Parent to Parent were Caucasian (88%), with 90 percent of the respondents coming from a two-parent household and 35 percent of respondents earning over \$50,000 per annum. Santelli et al.'s (1995) study also looked at what factors were involved with the Veteran Parent match; for example, whether or not the family members had similar disabilities or whether or not the families faced similar problems. Parents were able to rate the importance of these factors, with the two aforementioned receiving the highest ratings of 76 percent and 63 percent respectively. Fifty percent of the participants had a match that had lasted for more than a year and 56 percent had had at least 7 contacts. This research was used to assist with the design of a five-year longitudinal study that will be discussed later.

Santelli, Turnbull, Sergeant, Lerner, and Marquis (1996) followed on from the above study using the same national survey. They looked further at parental preferences for support using the same 240 referred parent surveys from the 1995 study. This study divided the data on preferences for support into subgroups based on the severity of the child's disability and the age of the child. There were

trends that occurred across age and severity of disability with the majority of respondents stating that having someone to listen to them and understand their situation was their preferred form of emotional support. Those with older children also showed a strong preference for seeking help in feeling less alone and for problem-solving. Regardless of age, parents also had a strong preference for group meetings. Preferences around information support were also considered. Trends across all ages were established, with all parents seeking information on their child's disability, the availability of community resources and services, how to find and get help, and how to care for their child.

In 1998, Ainbinder, Blanchard, Singer, Sullivan, Powers, Marquis, Santelli, and the Consortium to Evaluate Parent to Parent, published a study that used a subset of the population used in Singer, Marquis, Powers, Blanchard, Divenere, Santelli, Ainbinder and Sharp (1999). Ainbinder et al. (1998) used this subset of respondents to provide in depth qualitative information gathered from phone interviews to support the quantitative data from the Singer et al. (1999) study. Transcriptions of the interviews were coded and analysed and from these it was discovered that to have a successful match between Veteran Parents and supported parents the former must be seen as a 'reliable ally' by the latter. To achieve this 'ally' status, four key criteria must be met. First, there must be a feeling of perceived sameness, where the parent seeking support recognises that the Support Parent has 'walked in their shoes' (Ainbinder et al., 1998). Second, the relationship must enable the parent seeking support to be able to learn from the Support Parent; this learning could be as simple as receiving tips for toilet training or behaviour issues. Third, the 'ally' status is achieved by the supported parent having someone who is available whenever they are needed for support. Finally, the 'ally' status is achieved by the 'mutuality of support', which is when the support is bi-directional and the Support Parent also gains from the relationship.

In 1999, research was undertaken to evaluate a sample of Parent to Parent programmes in USA using quantitative data. Singer et al. (1999) divided their participants into a treatment or control group, with the groups compared on measures of coping, attitudes, and their progress on addressing problems. Although the majority of the parents involved in the study (61%) had only one or two contacts with their Veteran Parent the study found statistically significant improvement in parental self reports in the treatment group in the measures on coping with their child and family situation. The participants were also able to view their situation in a more positive light. This study was one of the first that could quantify that belief that although professionals can offer information and guidance, this was not the same as the support provided by a Veteran Parent who offered similarity of lived experience.

In New Zealand, Parent to Parent has completed social audits in 1999 and 2005. The 2005 social audit investigated eight social objectives. Of the eight objectives, three included information that is relevant to the current study. The first relevant objective was to determine whether or not Parent to Parent was finding appropriate matches for the supported families. Of the participants that had requested to be matched with a Support Parent, 17 (59%) indicated that the match met their needs, eight participants (28%) stated that the match did not meet their needs, and four participants did not respond to this question. The second pertinent objective was to establish if the provision of information to requesting families met their needs, and was the accurate information available. Twenty participants (84%) were satisfied with the length of time it took for their information to arrive, two participants (8%) were not satisfied and two (8%) participants did not respond to the question. The third relevant objective was to determine whether or not Parent to Parent NZ provided support and empowerment to family caregivers through their workshops and sibling workshops. The feedback from the audit on the various courses and workshops was positive, with participants reporting increased confidence and knowledge, and support for their situation (Parent to Parent, 2005).

In 2013, Bell, Fitzgerald, and Legge released a technical report that was part of a wider study titled *Troubling 'Choice': Exploring and Explaining Techniques of Moral Reasoning for People Living at the Intersection of Reproductive Technologies, Genetics and Disability*. The technical report involved the authors working alongside Parent to Parent NZ to explore how they approach supporting those that sought information about starting a family when they have a family member with a disability. The research involved interviewing paid employees of Parent to Parent (current and former) and an individual who worked voluntarily for the organisation. Of the 15 participants, nine were also Support Parents. Whilst this is not relevant in the aspect of the effectiveness of support, the report summarises Parent to Parent in New Zealand and their role as information providers.

At the time in which this research was undertaken, there has yet to be another social audit completed by Parent to Parent NZ. Whilst the social audits provide valuable information to the organisation, in-depth demographic information of the parents seeking support along with their perceptions on the usefulness of the service is lacking. Since the late 1990s it has been noted that there is a body of anecdotal evidence that supports the value of the peer support relationship; however, rigorous evaluation of the peer support offered by Parent to Parent with quantitative data is lacking (Ainbinder et al, 1998). As previously discussed, Singer and colleagues (2012) summarised

Parent to Parent services across the Pacific Rim and the point was made that although the evidence suggests that Parent to Parent is a valued service both in New Zealand and in other countries, there has been no published research on the effectiveness of Parent to Parent NZ.

## **2.6 Research Questions**

Based on the literature search, and the paucity of current research information within the New Zealand context, three distinct but related themes were identified for the purposed of this thesis, namely:

Part 1 – To establish who is using Parent to Parent NZ.

Part 2 – To establish why they are accessing Parent to Parent, and what services they are accessing.

Part 3 – To establish whether parents paired with a Support Parent, for peer support, find the experience useful.



## **Chapter 3 – Methods and materials**

The aim of this chapter is to describe the methods and materials relevant to answering the research questions articulated in Section 2.6. The presentation of this chapter was informed by the STROBE guidelines for cross-section studies (see: [http://www.strobe-statement.org/fileadmin/Strobe/uploads/checklists/STROBE\\_checklist\\_v4\\_cross-sectional.pdf](http://www.strobe-statement.org/fileadmin/Strobe/uploads/checklists/STROBE_checklist_v4_cross-sectional.pdf)).

### **3.1 Study design**

A national cross-sectional design was employed, utilising an electronically delivered questionnaire via the SurveyMonkey® ([www.surveymonkey.com](http://www.surveymonkey.com)) platform.

### **3.2 Setting**

Given the target audience are busy parents, having an online survey was considered to be the optimal strategy to obtain the maximum possible responses. It is evident in the literature that internet methods are of the same quality as paper-and-pencil based studies (Gosling, Vazire, Srivastava & John, 2004). The timing of the release of the survey was to avoid the school holidays in New Zealand (when parents are traditionally kept busy with increased childcare duties). To allow for a live test, the SurveyMonkey® link was activated on the 13<sup>th</sup> April 2015. The test was completed by the author, another independent parent and the study supervisors. Following this test, the study was advertised across multiple mediums including Parent to Parent NZ's autumn magazine. A full list of where the survey was advertised can be found in Table 3.1. Following the publication of the magazine on 1<sup>st</sup> May 2015, the first responses were received on 4<sup>th</sup> May 2015. The link to the survey was initially scheduled to be live until Sunday 21<sup>st</sup> June 2015. However, due to a low response rate the author contacted the Communications Advisor at Parent to Parent NZ, who advised that there was an upcoming meeting of management and regional coordinators a few days later. The intention was to promote the study with a discussion so the co-ordinators present could then regionally promote the study in a final drive for participants. For this reason the link to the survey remained live for an additional week until the 28<sup>th</sup> June 2015.

### **3.3 Target Population**

To meet inclusion criteria for the study, participants needed to have been matched with a Support Parent. Participants were recruited via Parent to Parent utilising their existing social media and print publications. All those involved in the Parent to Parent programme since it was established in 1983, and who had been paired with a Support Parent, were eligible. Participants were any parent who had contacted Parent to Parent for support, with the advert used for recruitment specifying that the participant be matched with a Support Parent at the time of taking the survey. Although not all participants were matched with a Support Parent, their responses were not excluded from analysis of the information gathered from the questions in Part 1 and 2. Furthermore, those that were not matched with a Support Parent at the time of taking the survey were unable to answer the questions in Part 3 of the questionnaire, therefore these participant's responses to this section were not part of the final analysis of Part 3.

In the information letter that was provided at the beginning of the survey it was specified that if participants began the questionnaire and subsequently decided that they did not want to continue, they should exit the browser and their responses would not be kept or used for the study.

Parents are often referred to Parent to Parent at the time of diagnosis of their child's disability, special needs, or chronic health condition. Anyone can refer a parent and parents can self refer. Parent to Parent have a database of those who have contacted Parent to Parent and at the time of the study this number was 10,600.

### **3.4 Instrument**

This study used a simple online questionnaire which contained 28 questions that were presented in 3 parts. It sought to collect quantitative data with numerous opportunities for participants to provide comments which were used to enrich the quantitative data. It was anticipated that the questionnaire would take participants 10-15 minutes to complete. In the initial stages of questionnaire design the author, supervisor, Parent to Parent NZ General Manager and CEO met to discuss what would be in the questionnaire. It was hoped that the study would provide information that was useful to Parent to Parent, it was at this time that concerns around responder burden and the ethics of having a control and test group were also discussed. The original design of the questionnaire was modelled off Singer et al. (1999); however, the design of the questionnaire was amended to reflect the above concerns and to address the three research questions.

Part 1 sought to answer the first research question “who is using Parent to Parent” and gathered primarily demographic information (e.g., disability type, whether the participant was parenting alone or with a partner, the location of the participant, and the participants’ ethnicity) in order to establish who was accessing services through Parent to Parent. The majority of questions in Part 1 consisted of tick boxes from preselected categories. Question six sought to determine what type of disability, special needs or chronic health condition the participant’s child had, the participant had the ability to type their own responses for this question.

Part 2 gathered information to answer the second research question “to establish why they are accessing Parent to Parent, and what services they are accessing”. The questions included “*What is the main reason you contacted Parent to Parent*”. At the end of Part 2 participants were asked if they had any comments on the question “*Would you recommend Parent to Parent to another parent – please explain*” and “*Is there anything you would like to comment on regarding the services provided by Parent to Parent*” (see Appendix E for the full questionnaire). The study sought to collect quantitative data with numerous opportunities for participants to provide comments which were used to enrich the quantitative data.

Part 3 sought to answer the research question “whether parents paired with a Support Parent, for peer support, find the experience useful”. The main component of Part 3, were eight questions on a five-point Likert scale. Participants were able to select strongly disagree through to strongly agree and included a neither agree nor disagree option. There was also an option of “Not Matched with a Support Parent” for participants who had not been matched. The Likert scale questions in Part 3 were adapted from the measures used in Singer et al. (1999) and Santelli et al. (1998). These studies used new and existing scales to measure coping, attitudes, empowerment and progress on addressing the problems faced by parents of a child with a disability. These scales included the Kansas Inventory of Parental Perceptions (KIPP), The Family Empowerment Scale (FES), the Parent Coping Efficacy Scale (PCES), and the Social Provisions Scale (SPS). Dr Jean Ann Summers (Beach Centre on Disability, USA) provided a copy of the user manual for the KIPP along with a copy of the scale itself and a copy of the Psychological Empowerment Scale, which has replaced the FES. Dr Daniel Russell (Iowa State University, USA) also provided a copy of the SPS. While the aforementioned scales were not used directly in this study, their content served as a starting point for the development of the questions that were presented to the participants in this study. The original scales were not used in order to reduce responder burden, as it was advised that the survey

would take too much time and would place too high an emotional and cognitive toll on the participants.

### *Māori Consultation*

Māori consultation was sought through the School of Health Sciences at Canterbury University. Māori health researcher Annabel Ahuriri-Driscoll suggested changes to the questionnaire, the information letter that was presented to the participants, and the application for ethical approval that was made to the Human Ethics Committee at Canterbury University. As part of her feedback, Ahuriri-Driscoll recommended changing the term ‘greater whānau’ to ‘wider whānau’ in the questionnaire. She also advised that participants should be asked which ethnic group they *identified* with in lieu of being asked which ethnic group they *belonged* to and she recommended increasing the available options for participants to choose from.

### *Piloting*

After ethical approval was given by the Human Ethics Committee at the University of Canterbury, the questionnaire was loaded on to the SurveyMonkey® platform with assistance from Amanda Duncan who was familiar with SurveyMonkey® (see signed confidentiality agreement, Appendix F). The online questionnaire was then piloted by three parents of individuals with a disability and one individual who worked for a disability service provider and were known by the author. The survey was piloted in order to determine whether it was (a) fully functional online, (b) readily comprehensible for the participants involved in the pilot, and, (c) formatted correctly. No data was collected while the questionnaire was still in ‘editing mode’ on SurveyMonkey® (‘editing mode’ allows for changes to be made to the uploaded survey).

Following the pilot phase, the questionnaire underwent various changes. For example, a check box was placed next to questions that had the option of “other” to address an oversight in the transfer of the questionnaire from a paper-based draft to an online format. Furthermore, Question 3 was rewritten to clarify the types of additional support that could be given (such as emotional and practical support). A new question was inserted into the questionnaire in Part 1 in order to explicitly ask the participants whether or not they had been matched with a Support Parent. In order to better determine whether or not a support relationship existed between the Support Parent and the supported parent, the wording of Question 10 was altered from “Following being connected with a

Support Parent have you continued to be in contact with your Support Parent?” to “Following being connected with a Support Parent do you have an ongoing relationship with your Support Parent?”. The wording of Question 11 was altered from “What was the most common method you used to connect with your Support Parent?” to “What was the method of communication you used that was the most meaningful?”. Question 14 was changed from “If you contacted Parent to Parent for information please tick the box that best applies” to “If you contacted Parent to Parent for information, please tick the box that describes the information you received”. Question 15 received a minor change as the question “If you contacted Parent to Parent for emotional support which of these best describes the key reason?” was replaced with “If you contacted Parent to Parent for emotional support what best describes the reason for contact?” An additional question was added to Question 18 which only appeared if a participant responded with a “yes” to Question 18 (the new question was “If yes, please state”). A further additional question was added to Question 20 (formerly Question 19); the additional question asked for an explanation of the respondent’s answer to the previous question.

Once the survey went live, a final trial was conducted on the live format as there were minor differences with the pilot version (as it was still in ‘editing’ mode on the site) versus what participants could do in terms of navigation. This response was coded by SurveyMonkey® as participant one. Before the data was collated for analysis this response was deleted.

### **3.5 Procedure**

Participants for the study were recruited via Parent to Parent NZ’s existing print and social media. The participants were self selected in that after seeing the advertisement they selected whether they would like to participate in the study. Parent to Parent NZ has a database of parents who have sought support from them, with information held at both a national and regional level. Parent to Parent has a national magazine that is published quarterly and is in both print and electronic format. Regions and national office also have their own Facebook pages and twitter feed. The Communications Advisor at Parent to Parent NZ organised the placement of the advert (see Appendix G) in the national magazine and distributed the advert to the regional offices. The regional offices then made the decision whether to include the advertisement in their electronic newsletter, Facebook pages and Twitter feed (see Table 3.1). The advertisement had a link that when in electronic form would lead directly to the survey. When in print form the participant would need to type the link into their web browser’s navigation bar. Prior to the closing date, contact was made

with the Communications Advisor due to the low number of responses, and in conjunction with the CEO it was decided to extend this for another week and attempt to recruit further participants. The Communications Advisor advised that a meeting of all the regional co-ordinators was occurring just after the original closing date, and suggested that the study be mentioned at this meeting. It was hoped that the regional co-ordinators would be able to attempt one final push by discussing the study with those eligible.

Table 3.1 – Parent to Parent publication of the advertisement for the study across date, medium and where known the number of people who have access to that medium

Area	Medium	Date	Number of people reached (if known)
National Office	Magazine	7 May 2015	1000
National Office	Website	7 May 2015	
National Office	Facebook	8 May 2015 and 28 May 2015	
National Office	Twitter	15 June 2015 and 16 June 2015	
Auckland	E-News	27 May 2015	230
Waikato	E-News	Data not supplied	
Central Lakes	E-News	May edition 2015	
Manawatu	E-News	May edition 2015	
Manawatu	Facebook	20 May 2015	35
Wellington	E-News	May edition 2015	718

The first page participants would see prior to the survey was the information page; at the end of the information page was a tick box to confirm that the information page has been read and understood before the survey could be continued. The full information letter can be found in Appendix H. Due to the anonymity of responses this method was chosen for giving consent so the participants did not have reveal any information about themselves by signing a consent form. Participants were given the option of including an email address at the end of the survey to be sent a copy of the completed thesis. This was kept separate from all other materials and was only accessible to the lead researcher. In the information letter participants were advised that if answering the questionnaire raised any issues or emotions for them that they could contact their Support Parent or the General Manager of Parent to Parent NZ, and her contact information was supplied. If participants had any questions about the study itself, supervisor Garry Hornby's contact email was supplied.

### **3.6 Data management and analysis**

All data from the survey was able to be kept securely on the password protected SurveyMonkey® website, before being downloaded into MS Excel files. Quantitative variables were then exported into a specialist statistical package Stata version 14.1 (StataCorp, College Station, Texas, USA) for analysis. Reporting and analysis were informed by the STROBE guidelines for cross-section studies. Participant flow and numbers were initially described, followed by descriptive analysis of the sample – in terms of ethnicity, geographical location, parental status and supports, and condition of the child. A descriptive account then followed of the various questionnaire domains. Unfortunately, initial plans to consider investigating data patterns through regression analyses were unable to be completed due to the low response rate. However, Fisher's exact test was employed to compare categorical variables, such as whether someone was parenting alone had any impact on the participant's responses in Part 3 of the questionnaire which considered the impact of the Support Parent on the parent seeking support. For all statistical comparisons, an  $\alpha=0.05$  defined significance.

For the qualitative component of the survey, participants were able to leave comments at the end of Part 2 and 3 of the survey. These were intentionally broadly framed to capture any opinion the participant had on the services provided by Parent to Parent and their Support Parent match. It was decided that coding the comments would reduce the impact of what participants were saying and therefore the comments were put into tables as they were written. Themes from the comments are discussed in the discussion whilst being compared to themes from the international research. These themes include the concept of perceived sameness, learning of practical skills and information and personal growth. They were then categorised by key phrases or terms used by the participant in their comment.

### **3.7 Ethics**

Ethical approval was gained from the Human Ethics Committee of the University of Canterbury, New Zealand, on 2 February 2015. A copy of ethical approval is attached in Appendix A. By using the platform of SurveyMonkey® and not requiring any personalised information the anonymity of the participants was protected. The ability to login to SurveyMonkey® and thus the participant's responses was only available to the author and Amanda Duncan, who helped load the questionnaire. Participants were able to leave their email address at completion of the questionnaire if they wished to be informed of the study or receive a copy of the thesis. This information was kept in a password

protected document with the login to the computer and document known only to the author. The first page which the participants would see before accessing the questionnaire was the information sheet (see Appendix H). The information sheet specified that the study is independent of Parent to Parent. It also detailed that they had the right to withdraw at any stage and could do this by closing the browser, but, due to the anonymity of the study after their responses were submitted they would be unable to be withdrawn. At the end of the information letter participants were advised that by continuing to the next page they were providing their consent to participate in the study.

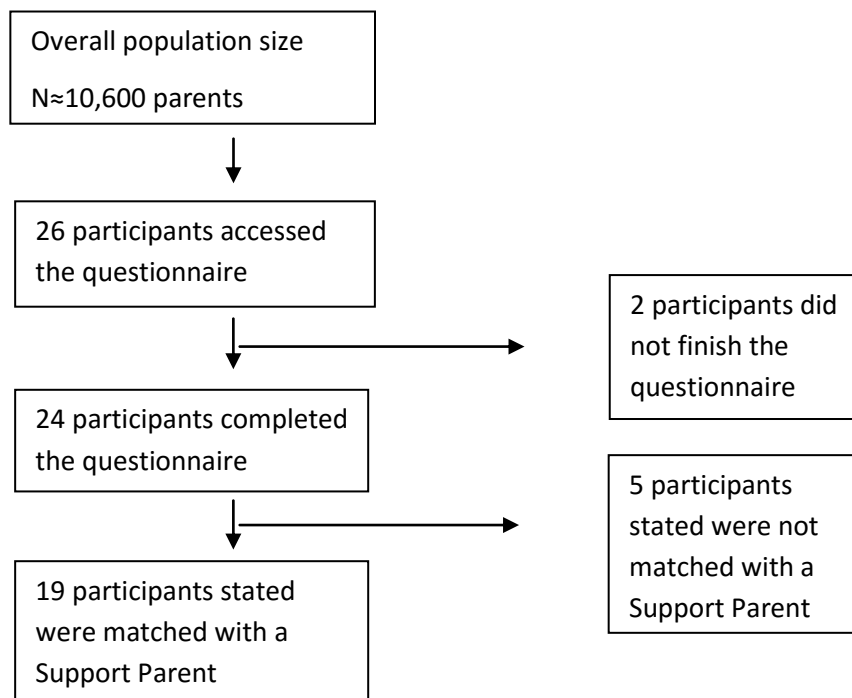


## Chapter 4 – Results

### 4.1 Survey response rate

Overall, 24 people were recruited to the study. Figure 4.1 depicts participant flow from the original sample pool, which was estimated to be 10,600 parents. Of the 26 people who accessed SurveyMonkey® and began the questionnaire, two closed the questionnaire on their internet browser before the completion of the survey. The remaining 24 participants' responses were analysed for Part 1 and Part 2; however, five participants stated in Question 8 that they were not matched with a Support Parent. Accordingly, their responses to Part 3 of the questionnaire were not deemed relevant to the later analysis. This left the remaining sample size for Part 3 of the survey, at 19.

Figure 4.1. Participant flow during the recruitment process.



### 4.2 Characteristic of the Sample

Demographic, geographical, and child disability distributions of the participants appears in Table 4.1. In terms of the ethnicity of the participants, 21 (88%) identified as being New Zealand European, one

(4%) of the participants identified as being Māori, one (4%) identified as being both Māori and New Zealand European, and one (4%) stated 'other' and identified themselves as Indonesian.

As Table 4.1 shows, the participants' geographical locations were diverse, with the majority of the regions of New Zealand represented. Given that the Waikato and the Manawatu are not the most populated regions in New Zealand, it was surprising that these geographical locations provided the most participants per region in this study (with five participants coming from each region). While the small sample size means that it is not possible to conduct an analysis on whether the regional variation presents a statistically significant difference, it is still interesting to note that the most participants per region did not come from key urban centres such as Auckland, Wellington, and Christchurch. Although the participants of this study were spread throughout the country, the low response rate has meant very little can be used from the regional data. Certainly, comparisons to Census data or other national profiles would offer little insight.

The 2013 Census reports that there were 1,136,397 families in New Zealand at the time the information was gathered; of these, 381,222 (34%) were two-parent households with dependent children under the age of 18 years (Statistics New Zealand, 2015). However, in this study, 19 participants (79%) stated that they were parenting with a partner. Furthermore, the 2013 Census reports that there were 144,777 (13%) single-parent families with dependent children in New Zealand (Statistics New Zealand, 2015); whereas in this study there were five participants (21%) who were parenting alone. When asked about the support they received, the participants were able to select one or more of the five options presented; 15 participants (62%) had the support of their immediate family, six participants (25%) had the support of their wider whānau (or extended family group), one participant (4%) had 'other' support in the form of their paediatrician, and seven participants (29%) stated that they had no other support. Interestingly, the participant who reported that they received support from their child's Paediatrician was the only reference made by any participant to professional support.

Participants were able to write up to 300 characters to provide a description of their child's diagnosis, answering the question "what type of disability, health condition or special needs does your child have?". These diagnoses were often complex with the participants reporting that their children had multiple disabilities or health conditions. Many of the diagnoses fit into discrete categories and were hence coded for simplicity and anonymity. As Table 4.1 presents, six participants (25%) stated that their child had Autism Spectrum Disorder (ASD), the children of three

participants (12%) had a chromosomal abnormality (e.g., Down Syndrome), seven of the participants' children (30%) presented with complex multi-diagnoses, which may include multiple other categories (e.g., epilepsy, ASD and intellectual disability), two of the participants' (8%) children had an intellectual disability (ID), five participants' (21%) children had a medical diagnosis only (for example febrile convulsions and gluten intolerance), and one participants' child (4%) was in the 'other' category. The participants' data was placed into the 'other' category as the child's diagnosis was Attention Deficit Hyperactivity Disorder (ADHD). Information was also gathered on the severity of the child's disability, health condition or special needs, based on the participants' perception of that severity. Four participants (17%) rated their child's condition as mild, nine participants (37%) rated their child's condition as moderate, six participants (25%) rated their child's condition as high needs, and five participants (21%) rated their child's condition as very high needs.

Table 4.1. The participants' aggregated responses to Questions 2-7 of Part 1 of the online questionnaire.

	n	(%)
<i>(Q4) Ethnicity of participants</i>		
Māori	1	(4)
NZ European	21	(88)
Māori & NZ European	1	(4)
Other <sup>1</sup>	1	(4)
<i>(Q5) Region</i>		
Northland	1	(4)
Auckland	3	(13)
Coastal Bay of Plenty	3	(13)
Waikato	5	(21)
Central Lakes	1	(4)
Manawatu	5	(21)
Wellington	2	(8)
Canterbury	1	(4)
Otago	2	(8)
Southland	1	(4)
<i>(Q2) Parental relationship</i>		
Alone	5	(21)
With a partner	19	(79)
<i>(Q3) Family support</i>		
Immediate family	15	(62)
Wider whānau (extended family group)	6	(25)
Support Groups	1	(4)
Other <sup>2</sup>	1	(4)
No other support	7	(29)
<i>(Q6) Condition of the child</i>		
Autism Spectrum Disorder	6	(25)
Chromosomal	3	(12)
Complex multi diagnosis	7	(30)
Intellectual disability type not specified	2	(8)
Medical	5	(21)
Other	1	(4)
<i>(Q7) Severity of disability / health condition</i>		
Mild	4	(17)
Moderate	9	(37)
High	6	(25)
Very High	5	(21)

Other<sup>1</sup> was Indonesian

Other<sup>2</sup> was a Paediatrician.

Having asked the participants for details about their ethnicity, geographical location, support networks, and children's disability, chronic health condition, or special needs, the remaining question of Part 1 focused upon the relationship between the participant and their Support Parent. As Table 4.2 presents, 13 participants (68%) had experienced 0-1 contacts with their Support Parent

at the time the information was gathered, two participants (11%) had experienced 2-4 contacts, and four participants (21%) had experienced five or more contacts with their Support Parent. Of the 19 participants who provided responses to the final questions of Part 1, only five (26%) reported that they still had an ongoing relationship with their Support Parent. Accordingly, the remaining participants reported on their most common method for connecting with their Support Parent, with three participants (60% of those who answered the question) stating that they communicated with the Support Parent by phone, one participant (20%) reporting that they met their Support Parent in person, and one participant (20%) reporting that they communicated with their Support Parent via an online medium (such as email, Skype, or Facebook).

Table 4.2. The participants' aggregated responses to Questions 9-11 of Part 1 of the online questionnaire.

	n	(%)
<i>(Q9) Number of contacts with the Support Parent</i>		
0-1	13	(68)
2-4	2	(11)
5+	4	(21)
<i>(Q10) Do you have an ongoing relationship with your Support Parent</i>		
Yes	5	(26)
No	14	(74)
<i>(Q11) The most common method for connecting with the Support Parent</i>		
In person	1	(20)
Online – such as email, Skype or Facebook	1	(20)
Over the phone	3	(60)

### 4.3 Why participants access Parent to Parent, and what services they are accessing

Many of the questions in Part Two of the online questionnaire begin with an “if” statement; accordingly, the values in the *n* column of Table 4.3 represent data produced by only those who responded to such “if” statements. As Table 4.3 presents, more participants (*n*=11, 46%) stated they contacted Parent to Parent NZ for information than to be connected with a Support Parent (*n*=5, 21%) and four participants (17%) reported that they contacted Parent to Parent NZ for emotional support. Participants were then asked whether or not they had contacted Parent to Parent NZ on only one occasion and, if so, what the reason for that contact was. In response to Question 13, seven participants' (33%) stated that they got the information they had needed from the one contact, seven participants (33%) stated they had been matched with a Support Parent, four participants (19%) had contacted Parent to Parent NZ to find out more about the organisation, and the remaining

participants made contact to access emotional support or for other reasons. Of those participants who accessed Parent to Parent NZ for information, 11 participants (50%) sought information related to their child's disability or condition, six participants (27%) sought information on an issue related to the disability or condition, and five participants (23%) sought information on a variety of other matters. Of those participants who contacted Parent to Parent NZ for emotional support, eight participants (36%) reported that they accessed the organisation's services to help them "feel less alone", five participants (23%) accessed Parent to Parent NZ in order to have someone who is able to listen to them and understand their situation, four participants (18%) stated that they accessed Parent to Parent NZ's service to better deal with their son or daughter's diagnosis, three participants (13%) accessed Parent to Parent NZ so that they could receive support in problem solving, and one participant chose the 'other' option. In Question 16, the participants were asked to state which of the services provided by Parent to Parent NZ they found most useful. There were a high number of responses to this question with 16 participants (67%) reporting that they found Parent to Parent NZ's information service useful, followed by information of supports and services and how to access them (n=12), being connected with a Support Parent (n=11), training and workshops (n=11), and coffee and support group get-togethers (n=10) were also popular responses. The popularity of these services was reflected in the following question around future access to services. All of the aforementioned services received almost identical response rates for example information on the disability or condition (n=12) and being connected with a Support Parent (n=11).

Table 4.3. The participants' aggregated responses to Questions 12-17 of Part 2 of the online questionnaire.

	n	(%)
<i>(Q12) What is the main reason you contacted Parent to Parent</i>		
Emotional Support	4	(17)
For advice on a specific issue / problem	1	(4)
Information	11	(46)
Other <sup>1</sup>	1	(4)
Support for sibling or other family member	2	(8)
To be paired with a Support Parent	5	(21)
<i>(Q13) If you contacted Parent to Parent on only one occasion what best describes the reason</i>		
I got the emotional support I needed	2	(9)
I got the information I needed	7	(30)
I wanted to know what Parent to Parent was about	4	(18)
I was connected with a Support Parent	7	(30)
Other <sup>2</sup>	3	(13)
<i>(Q14) If you contacted Parent to Parent for information which of the below is most applicable</i>		
Financial information or advice on financial options	1	(4)
Information about your child's disability or condition	11	(48)
Information on an issue relating to your child's disability	6	(26)
Information on other services	2	(9)
Information on community resources	2	(9)
Other <sup>3</sup>	1	(4)
<i>(Q15) If you contacted Parent to Parent for emotional support which best describes the reason for contact</i>		
Help in feeling less alone	8	(36)
Help with dealing with the diagnosis	4	(18)
Hope for the future	1	(5)
Other <sup>4</sup>	1	(5)
Problem solving support	3	(13)
Someone to listen and understand	5	(23)
<i>(Q16) Of the services provided by Parent to Parent please tick all those you have found useful</i>		
Adult sibling support programmes	1	(4)
Being connected with a Support Parent	11	(46)
Child sibling support programmes	6	(25)
Coffee and support group get-togethers	10	(42)
Family camps and activities	4	(17)
Information on the disability/condition	16	(67)
Information of supports and services and how to access	12	(50)
Other <sup>5</sup>	1	(4)
Training and workshops	11	(46)
<i>(Q17) If you were to use Parent to Parent in the future what services would you use</i>		
Adult sibling support programmes	4	(17)
Being connected with a Support Parent	11	(46)
Child sibling support programmes	8	(33)
Coffee and support group get-togethers	11	(46)
Family camps and activities	5	(21)
Information on the disability/condition	12	(50)
Information of supports and services and how to access	11	(46)

Other<sup>1</sup> – advice

Other<sup>2</sup> – I didn't manage to get to the support groups; I have contacted them repeatedly but I was disappointed at the result; I contacted them more than once

Other<sup>3</sup> – Did not contact for info

Other<sup>4</sup> – all of the above really!

Other<sup>5</sup> – No thanks

In Question 18, participants were asked whether there were any additional services that they would find useful if they were to use Parent to Parent in the future. Furthermore, the participants were given the opportunity (by a drop-down box resulting the data being under the title Question 19) to describe the specific service they would access. Seven participants stated there would be additional services they would like to access with six of these commenting.

Table 4.4. The comments provided by the participants who responded to Question 19 of Part 2 of the online questionnaire.

Participant ID	Comment
<i>(Q19) If you were to use Parent to Parent again, would there be any additional services that would be useful to you. If yes please state</i>	
2	Access to child psychologist
3	how to train and guide my dispraxia and aspergers daughter
8	Parent to parent should do what their documentation states - they say one thing (sounds very good) but do not act as they say
11	be able to do it online (not just email)
13	Sibling support
21	Finding out about my entitlements with other agencies i would like to do respite care for others I would like to become a support parent
23	Sibling support, more contact from support person

Participants were then asked would they recommend Parent to Parent to another Parent, 18 participants' (75%) said yes, 4 participants' (17%) said maybe and 2 participants' (8%) said no. There was then a chance for participants to give an explanation for their answer, 14 participants answered this, with 10 skipping the question. Comments that were made by participants in response to the questions: "Would you recommend Parent to Parent to another parent?" and "Is there anything you would like to comment on regarding the services provided by Parent to Parent?" appear in Table 4.4.



Table 4.5. The comments made by participants in response to Questions 21 and 22 of Part 2 of the online questionnaire.

Participant ID	Comment
<i>(Q21) Would you recommend Parent to Parent to another parent – please explain</i>	
1	Being connected to a support parent who understood my experience without me having to explain every little detail to her was a life saver. The feeling of isolation I had been experiencing lifted and I felt hopeful for the first time in a very long time. The support parent experience was so powerful for me that I trained as a support parent myself and joined the local committee. Even 8 years on, I still feel extremely grateful to the lovely support parent who supported me and inspired me to "pay it forward" by doing the same thing for others.
3	I don't see the benefit except the information only.
5	Only someone who is or has walked in your shoes understands what you a going through
8	Parent to parent receive enormous funding from private and government sources - they do not deliver on what they promise. What I am most furious about is that I am counted amongst their parent database - even though they have not fulfilled their pledge.
9	They are very open and helpful very good listeners have excellent information can share life experience that relate to you.
10	The connection with a parent with a similar disability is priceless - for a start you don't have to explain things which causes emotional rollercoaster - often people assume you are seeking sympathy. The training programmes, especially for the carer are priceless, as is the knowledge that you can connect with your support parent in the future. My experience was not intense with my support parent, but the relationship continues to exist years later. The ability to gain accurate relevant and timely information instead of having to wade through technical journals and unreliable internet information is very useful.
11	Fabulous service, have had parent support and then onto being a support parent - p2p make you at the very least, listened to, supported, valued & not so isolated.
13	They haven't been a lot of help here in Central Otago I have started a coffee group myself but it sounds fantastic in Dunedin.
14	Great support.
15	It's a relief to feel connected to a service that is interest in your wellbeing as a parent and as a family, instead of clinicians focussing on the diagnosis of a child. It's good to feel normal by talking to people who feel the same.
18	I think parents are the best source of support for other parents, especially when the support is enabled through well monitored channels and in a positive and safe environment.
19	It was helpful for our family.
21	I think Parent to Parent offers so much more than any other service in New Zealand. Not only do they have information about lots of different disabilities but if they don't know about something they help you to search further or put you on to other people that can help. They

offer support parents you can talk to. They help assist with respite care, coffee groups, fun days/evenings etc. Parent to Parent is another friend/someone you can vent to when you feel you need help and they are always non-judgemental.

*(Q22) Is there anything you would like to comment on regarding the services provided by Parent to Parent*

- 6 I actually think the parent to parent support should be better. I got one phone call which wasn't really that helpful. To be set up in a coffee group or other type of support group in my area would have been good. It was rather limited. I did get good advice on how to access other groups in the area but Parent to parent wasn't the provider of those.
- 9 They have been a fantastic resource I am very pleased to use.
- 10 They need to continue. It is vital for parents to have an organisation like this and it is great to see the launch into second generation support initiatives. What would be great is for a database that is coordinated with the Police where respite carers are screened by the Police but the list is available to Parent to parent with a feedback mechanism whereby any 'dodgy' issues which make our children vulnerable are also captured. Increased education by Police on how disability is demonstrated in the general public is very important in order to reduce inappropriate arrest or court appearances, even prison sentences.
- 11 I just think they are fabulous :)
- 12 No.
- 13 I wish they had funding to help get more support in place for us parents in Central Otago.
- 16 Awesome!
- 17 Great information given and also support groups and things difficult to attend due to my work commitments and also having three children on my own my time is very limited.
- 18 All really positive but the one thing would be to always ensure that family events are held in environments that are easily accessible for children with mobility needs.
- 20 It is a shame that an older child cannot go on a sibling's camp if they have a minor health issue.
- 21 I highly recommend Parent to Parent to everyone. The support they give parents is amazing. They provide so much more than just a little bit of information.
- 23 Was disappointed after being recommended by a friend.
- 

#### **4.4 To establish whether parents paired with a Support Parent, for peer support, find the experience useful**

Participants were asked eight questions to establish whether the match with a Support Parent was of benefit to them. For example, these questions asked the participants retrospectively whether being matched with a Support Parent resulted in them feeling more empowered, better able to cope, and able to advocate for their child. The responses showed trends with the number of participants answering in either a, positive, negative, or neutral fashion showing little variation

between questions. For example participants 1, 16, 17, 19 and 22 answered almost completely with strongly agree. By comparison participants 18 and 20 answered with almost completely strongly disagree. Participants 8, 14 and 23 answered predominantly with neither agree nor disagree responses. This could be due to a predisposed mindset, where the participant had an overall negative or positive experience and therefore, even though their experiences may not have been entirely bad, the negative experience taints the overall experience and is reflected in their answers to these questions. Of concern is the high rate of negative responses to the question “Because of my match I feel like I have someone to talk to about my child’s disability” of 6 (32%). The primary cause of concern around this is the fact that this is the foundation of a peer support relationship, and it appears that for many participants this was not present.

Table 4.6. The participants’ aggregated responses on the perceived effectiveness of the match with their Support Parent.

	Strongly agree n (%)	Agree n (%)	Neutral n (%)	Disagree n (%)	Strongly disagree n (%)
<i>My Support Parent match worked for me</i>	8 (42)	4 (21)	4 (21)	2 (11)	1 (5)
<i>I believe my Support Parent match worked because we are/were in similar situations</i>	5 (26)	8 (42)	4 (21)	2 (11)	0 (0)
<i>Because of my match I feel like I have someone to talk to about my child’s disability</i>	6 (31)	2 (11)	5 (26)	3 (16)	3 (16)
<i>I felt like I could say anything to my Support Parent</i>	7 (36)	4 (21)	5 (26)	1 (5)	2 (11)
<i>Since my Support Parent match I feel empowered</i>	6 (31)	3 (16)	5 (26)	3 (16)	2 (11)
<i>Since my Support Parent match I feel that I can better cope with situations</i>	7 (36)	3 (16)	4 (21)	3 (16)	2 (11)
<i>Since my Support Parent match I feel that I can better advocate for my child</i>	4 (21)	5 (26)	6 (31)	2 (11)	2 (11)
<i>My Support Parent match has given me the confidence to make my own contacts</i>	6 (31)	5 (26)	3 (16)	3 (16)	2 (11)

Participants were asked what was it that the Support Parent did that was the most useful and were given the option of pre-selected responses from previous literature or to write their own comment. From this 12 (63%) participants felt the most useful thing their Support Parent did was “they shared from their experience”. This was followed equally at 3 participants (16%) “they listened to me” and “they gave me productive information”. Interestingly none of the participants chose the option of “they gave me advice”.

Table 4.7. The participants aggregated results for Question 24 of the online questionnaire.  
*(Q24) What was it that the Support Parent did that was most useful?*

	n	(%)
They shared from their experience	12	(63)
They gave me productive information	3	(16)
They listened to me	3	(16)
They gave me advice	0	(0)
Other <sup>1</sup>	1	(5)
Other <sup>1</sup> – specified above		

Following questions about the Support Parent that are presented in Table 4.6 and Table 4.7, participants were then asked if they had any comments on their Support Parent match. A basic thematic analysis of the comments occurred and this qualitative data is further discussed in Chapter 5.

Table 4.8. Comments made by participants in response to Question 25 of the online questionnaire.  
(Q25) *Do you have any comments surrounding your match with your Support Parent?*

Participant ID	Comment
3	Nope.
6	It was really only set up as a one -off phone call. Her child was much much older and really she had been there and done it all. A match with a family closer in age may have been better and to have ongoing support.
9	It was a great resource in a time of not knowing a lot about the condition my daughter had. They answer all my question and I have become a strong person because of them I can now advocate mail for your child well.
10	She was great and still is. It was comforting to know that she had completed a Support Parent course to help her in her role.
12	...just that I then became a support parent...in 1996.
13	What is a support parent?
14	We lost contact.
15	I did not maintain contact with my support person as it turned out my son was misdiagnosed, so that match was no longer accurate. She did, however, give me the hope and strength to research the conditions my son does have, to reach out for help, and to do things that my son needed even though they were not normal things that parents do. She also helped me accept that my son does actually have special needs, which made me feel less guilty for looking for answers for how to make his life better.
16	Although our children have the same conditions my child's is much more severe so support has been limited in that aspect. But it has been great to talk to someone who has been through some of the same things.
17	I would have liked more contact with her, I never got her phone number, she was going to email me but I never received the email and because of that I have no way of continuing contact.
18	Only that it was a long time ago when my son was a baby and it helped early on because it helped me to see I wasn't alone.
21	Although I did not get a match obviously due to the type of condition my child has it was really good to talk to someone that I could just vent to and someone that would listen understanding that the condition is rare like their child's.
23	Only had one contact with them. They did listen and offer advice but then never heard from them again.

In order to test for statistical significance between levels of support and severity of disability to the participants responses to Question 23, Fisher's exact tests were chosen due to its validity with small sample sizes (Moore & McCabe, 2003). For the Fisher's exact test, variables were grouped and only used the 19 responses that were classed as viable based off the participants' affirmative response to being paired with a Support Parent in Question 8. The first variable was the severity of disability

which was collated from the responses to Question 7 of the questionnaire. The question of severity was self defined with the question worded “what level of disability/special need/health condition do **you** believe your child has”. This self definition was specifically chosen due to the belief that participants may view the disability/special need/health condition as more severe when they are having difficulties with coping. It is acknowledged although the emphasis was on **you** in the question this may be skewed if participants instead went with severity as defined by whether the child for example was classed as high or very high under the Ongoing Resourcing Schemes (ORS) funding. Given that there were four different levels of severity classed in the questionnaire, these were dichotomised into mild/moderate and high/very high groupings. The second variable was taken from Question 2, no aggregation was required as the question provided the two variables of either parenting alone or with a partner. The third variable considered the wider supports available to the participant. Question 3 of the questionnaire gave four options, immediate family, wider whanau, other, or no support. Responses were collated to either support was provided or there was no other support. These three variables were then compared using Fisher’s exact test to the responses given by participants to Question 23, which consisted of eight questions. Table 4.8 presents the associated results. There were no statistically significant difference found across any of the variables comparisons. This is likely due to the small numbers small size, and will be discussed in the limitations section in chapter 5.

Table 4.9. *p* values for Fisher's exact tests performed on aggregated data from Questions 2, 3 and 7 against responses to Question 23.

	Low/moderate versus high/very high severity of disability (Q7)	Parenting alone or with a partner (Q2)	Presence or absence of wider support (Q3)
1	0.850	0.843	0.739
2	1.00	0.397	0.374
3	0.547	0.250	0.208
4	0.864	0.458	0.693
5	0.282	1.00	0.842
6	0.263	1.00	0.645
7	0.128	0.853	0.621
8	0.726	0.798	0.716

1 – My Support Parent match worked for me.

2 – I believe my Support Parent match worked because we are/were in similar situations.

3 – Because of my match I feel like I have someone to talk to about my child's disability.

4 – I felt like I could say anything to my Support Parent.

5 – Since my Support Parent match I feel empowered.

6 – Since my Support Parent match I feel that I can better cope with situations.

7 – Since my Support Parent match I feel that I can better advocate for my child.

8 – My Support Parent match has given me the confidence to make my own contacts.

## Chapter 5 – Discussion and Conclusion

### 5.1 Principal Findings

*“Being connected to a support parent who understood my experience without me having to explain every little detail to her was a life saver. The feeling of isolation I had been experiencing lifted and I felt hopeful for the first time in a very long time. The support parent experience was so powerful for me that I trained as a support parent myself and joined the local committee. Even 8 years on, I still feel extremely grateful to the lovely support parent who supported me and inspired me to “pay it forward” by doing the same thing for others”. – Participant ID=1*

This study had three objectives: (1) to ascertain who was accessing Parent to Parent, (2) to determine the services at Parent to Parent these parents were using, and, (3) to understand whether parents found the experience of being matched with a Support Parent to be useful. To achieve these objectives a three part questionnaire was created and advertised through Parent to Parent NZ’s networks. The findings of this study, the strengths and limitations of these findings and the implications are discussed below.

Parent to Parent NZ’s database contains information on approximately 10,600 parents. Of this sample, 24 (0.23%) completed the questionnaire, and 19 of the 24 parents had been matched with a Support Parent. As less than 0.5% of the target population responded to the survey, there are considerable limitations to the representativeness and generalisability of the study findings (Moore & McCabe, 2003). Moreover, there was negligible statistical power to identify patterns between sub-groups. This limits the external and internal validity of the survey’s results, and ultimately reduces its utility beyond a simple description of these responders responses.

#### 5.1.1 Part 1 – To establish who is using Parent to Parent.

The majority of survey participants (79%, n=19) indicated that they were parenting with the support of a partner. This is consistent with the findings of Santelli et al. (1995), who found that around 90% of participants in their study were in a two-person household. However these results are contrary to the findings of Reichman et al. (2008) and Hartley et al. (2010), who found that there are high levels of parental separation in parents who have a child with a disability. While all of the participants in



this study were the biological parent of a child with a disability, none of the questions in Part 1 of the survey established whether the participants were in a relationship with the other biological parent or whether they had remarried. So while this study has provided information that the majority of participants are parenting with the support of a partner, the nature of the spousal relationship has not been established.

The majority of the participants in this study who accessed Parent to Parent already had some form of established network providing them support. This included immediate family (n=15, 62%), wider whanau (n=6, 25%), support groups (n=1, 4%), and other (n=1, 4%). However, seven (29%) participants were parenting without any wider supports. Parenting a child with a disability can often be a complex and demanding task, Singer et al (2012) discussed how receiving informal support (such as spouses, relatives and other parents) can act as a protective factor against depression and anxiety, to parents of a child with a disability. While it is a minority in the study population, for the seven participants that stated they had no other supports, Parent to Parent could be their only access to those protective informal supports. Therefore, it would be these participants would be most at risk for stress, anxiety and depression. Identifying those that have no informal or “social” supports around them should be an important consideration for Parent to Parent NZ as it is these parents who are the most likely to require support and be more at risk in terms of their coping and wellbeing.

The majority of the participants who had received support from Parent to Parent that engaged in the current study were New Zealand European or Pākehā (88%). The ethnicity of the participants in this study can be compared to the ethnicity of the participants of Parent to Parent’s Social Audit of 2005. There were proportionally less New Zealand Europeans in Parent to Parent’s Social Audit of 2005 (n=25, 68%) compared to this study (n=21, 88%), with proportionally more participants who identified themselves as Māori (n=6, 16% vs. n=1, 4%). The smaller number of Māori and reduced number of ethnicities in this study may suggest that Parent to Parent is not providing services for as many non-European families as might be expected based upon their objective from the Parent to Parent Social Audit (2005) to expand the ethnic diversity of Parent to Parent. An alternative, and plausible explanation in that those of Māori ethnicity are less likely to respond to this method of information gathering. This is consistent with Maclennan, Kypri, Langley and Room (2012) who found a non-response bias for Māori, who were less likely participate in surveys on health related behaviours.

The majority of the participants in the current study indicated that they reside in the Manawatu and Waikato (n=5, 21%). The results of the current study are consistent with the Parent to Parent NZ Social Audit 2005, with respondents from every region participating with the exception of Nelson. Therefore, whilst the proportion of the targeted population captured was negligible, the fact that there was participation from almost every region in New Zealand is notable and a strength of this study.

In this study participants were asked to declare their child's disability, which often resulted in broad and multi-diagnosed conditions. As such, the highest proportion fell into the category of complex multi-diagnosis (n=7, 30%), and the second largest grouping as ASD (n=6, 25%). These findings are in contrast to Santelli et al. (1995) who found that in their study the smallest number of respondents were categorised as ASD (3%). Another interesting point of difference is in Santelli et al. (1995) Down Syndrome (29%) featured heavily, compared to chromosomal abnormalities (n=3, 12%) in the current study. It is possible that the difference between the current findings, and those of Santelli et al. (1995) is a result of the increase in prevalence of ASD (Tay, 2013).

In the current study the participant's perception of their child's disability, special needs or chronic health condition was distributed across the four severity levels, with the smallest number falling into the mild category (n=4, 17%) and the largest in moderate (n=9, 37%). Given that the child's level of disability was to be examined against the participant's responses to Part 3 of the questionnaire, it was decided emphasis should be placed on the level of disability the participant felt their child had. For this to occur the groups were aggregated for analysis with those reporting high and very high needs (n=11, 46%) compared to mild and moderate combined. In Singer et al. (1999) participants reported their child's disability to be mild (24.5%), moderate (44.8%) and severe (30.7%) across their intervention and waiting list group. Given that the severity of a child's disability can have a proportional impact on a family (Tay, 2013) it was expected that those who perceive their child's needs as high or very high would make up the highest proportion of participants, as they are most likely to need support. However, consistent with Singer et al. (1999), this was not seen. There are a number of possibilities for this and it is unknown whether those parenting children with high to very high needs are not accessing Parent to Parent or that they did not engage in the survey. Due to the high demands placed on those parenting a child with high or very high needs, it is possible that allocating time to answering a survey was not a priority for these parents. This could also hold true that those parents may also not have time to contact Parent to Parent and therefore ensuring availability of support is an important factor for Parent to Parent.

In the current study thirteen participants (68%) reported only having 0-1 contacts with their Support Parent. Ainbinder et al. (1998) gathered some quantitative information in their qualitative study from their participants on their Support Parent match to establish what is required for a successful match (a positive relationship between those seeking support and their Support Parent). The authors report a component of a successful match was an average of 5.75 contacts between the parents and their Support Parents. Therefore the low number of contacts from participants in the current study could be of concern. However, when the participants are grouped according to the number of contacts they had with their Support Parent, there are significant differences in their responses to Part 3 of the survey (questions included “since my Support Parent match I feel that I can better cope with situations around my child’s disability”). Participants 1, 11, 15 and 22 primarily answered agree and strongly agree to the questions in part 3 after only 0-1 responses. By comparison participants 3, 6, 18 and 20 answered disagree or strongly disagree. This could suggest that it is not necessarily the number of contacts made with a Support Parent that have a positive impact but the quality of the contact. Importantly, consistent with Ainbinder et al. (1998), all those in the current study who had five or more contacts answered either agree or strongly agree to 94% of the questions in part 3 (with the other 4% being neutral responses). Therefore, in the current study there was an approximate 50/50 chance of a match having a positive impact when there are only 0-1 contacts between the parent seeking support and the Support Parent. However, with the high number of positive responses from those that have multiple contacts with their Support Parent, ensuring the processes in place with Parent to Parent that follow up after an initial match are robust is an important and ongoing consideration for Parent to Parent.

*5.1.2 Part 2 – To establish why the participants are accessing Parent to Parent, and what services they are accessing.*

*“I think Parent to Parent offers so much more than any other service in New Zealand. Not only do they have information about lots of different disabilities but if they don't know about something they help you to search further or put you on to other people that can help.” – Participant ID=21*

A high proportion of the participants contacted Parent to Parent for information (n=11, 46%). As referrals are often made to Parent to Parent at the time of the child’s diagnosis, this is not a

surprising result. Parent to Parent's information service is often utilised to provide further information beyond what is provided by diagnosis alone. It would suggest that the participants are seeking information before they seek support. Santelli et al. (1996) demonstrated that parents who were surveyed generally use Parent to Parent USA and their Veteran Parent to access emotional, informational and other programmes support across the age of the child and the severity of their disability. Interestingly, they also found that although feelings of isolation are thought to be felt by parents in the early stages of their child's life, parents of older children were more likely than parents of younger children to seek help to support them to feel less alone or isolated. Regardless of age or the severity of the disability they found that at least 30% of parents are looking for: Emotional support – having someone to listen and understand; Informational support – having information about the disability, finding and getting services, living with and caring for the child, accessing community resources; and Other program supports – having group meetings for either emotional or educational support (Santelli et al. 1996).

The most common types of emotional support the participants in the current study were searching for were: wanting help in feeling less alone (36%), someone to listen and understand (23%) and help dealing with the diagnosis (18%). This is consistent with Santelli et al. (1995) who found that 66% of parents listed that having someone to listen and understand as the reason for seeking a parent match, followed by help in feeling less alone (35%), knowledge of others who are doing ok (34%), hope for the future (33%), way to deal with stress (21%) and problem solving support (20%).

Parent to Parent NZ offers a number of services; this can vary from region to region. Services include information service, being paired with a Support Parent, coffee groups, training and workshops, and sibling support. When participants were asked which services offered by Parent to Parent NZ they found useful, information provision, both on the disability/condition or supports and services available, rated the highest by 16 (67%) and 12 (50%) respondents, respectively. Services that involved connection with others such as a Support Parent connection (n=11, 46%) or support/coffee groups were the next highest (n=10, 42%). Training and workshops also rated as highly as support with 11 (46%) participants rating this as useful. This would suggest that Parent to Parent is viewed as more than a service that provides Support Parents, but as a single point of contact for provision of multiple services, that are viewed by the participants as useful. Family activities and siblings supports were not rated as high as other services, however, responses in the following question indicated a number of participants would access these in the future. It could be possible that participants were not aware of all of the services provided by Parent to Parent NZ. This appears to be the case with regard to sibling support, as in response to a question on whether they would find

any additional services useful, two participants commented on a need for having sibling support. Comparison data on similar service provision is scarce. Santelli et al. (1996) considered parents preferences for support, however, the support options differ from Parent to Parent NZ. Santelli et al. (1996) found that 49% of respondents found group meetings for emotional support useful, closely followed by 47% who attended group meetings for education. As seen with the current study, supports for the wider family such as social events (23%) and activities for other family members (9.5%) rated lower.

#### *5.1.3 Part 3 – To establish whether parents paired with a Support Parent, for peer support, find the experience useful*

*“...it was really good to talk to someone that I could just vent to and someone that would listen...” – Participant ID=21.*

The participant's responses to the questions in Part 3 were positive overall, with agreement on statements such as that their Support Parent matched for them. However, participants fluctuated on their level of agreement across the questions. This indicates that while participants found that the match worked for them, this possibly did not translate into participants feeling as though they were better able to cope with situations surrounding their child. There appears to be improvement in positive responses since the 2005 Social Audit, where it was found that 59% (n=17) felt their Support Parent match met their needs. In this study participants predominantly felt that their Support Parent match worked for them (n=12, 63%), however the quality of this relationship merits investigation, with numbers dropping to only eight positive (42%) feeling as though they now have someone to talk to about their child's disability/special needs/health condition. Also only 47% (n=9) felt empowered or 52% (n=10) more able to cope after being matched with a Support Parent. Although participants have generally been positive about their interactions with their Support Parent, the skill development that has previously been seen in other studies (Santelli et al. 1998) is not as strong in this particular sample. No significant differences were found in this study between the answers participants gave in Part 3 and the existing supports available to the participant (either through their partner or wider supports) and the level of the participant's child's disability.

Studies into the effectiveness of Parent to Parent have taken on a variety of approaches, looking at both qualitative and quantitative data with the majority of this research happening in the USA in the 1990s (Ainbinder et al. 1998; Santelli et al. 1995, 1996, 1998; Singer et al. 1999). Although there

have been different methods for collecting data around Parent to Parent, when it comes to why Parent to Parent works there are common themes. Perceived sameness between the parent seeking support and the Support/Veteran Parent, reduction in isolation, sharing from own experience and non-judgemental have been discussed in both Singer et al. (2012) and Santelli et al. (1998). Whilst these themes were not explored in-depth, the comments left by many of the participants echoed the themes of previous studies. As well as positive themes similar negative themes come through, only having one contact with their Support Parent, difficulty with access due to work commitments, physical access or areas not covered/with poor regional cover. Those themes that were found relevant to the current study are discussed below.

### *Perceived Sameness*

This is often considered the make or break point of the relationship between the parent seeking support and the Support Parent. Perceived sameness can occur on two levels: the children's situation and in the parents' personalities or parenting styles (Ainbinder et al. 1998). Singer and colleagues (1999) discuss perceived sameness and link this to Thoits' theory of social support in which individual's efforts to cope are supported and reinforced by the group (specifically self-help groups) modelling and giving practical advice. The perceived sameness of someone who has "been there" gives credibility to the advice that is offered, this can lead to an immediate positive relationship between the parents based on their mutual feelings of trust and understanding for the others situation, which doesn't exist within their other relationships, including with family (Ainbinder et al, 1998). Kerr and McIntosh (2000) discussed subgroups of this finding that parents discussed the realisation that you are not alone, that there is someone who was in a similar situation and therefore truly understands, and that speaking to a parent of a child who was similar but older provided a glimpse into the future that reassured the parents involved. Singer et al. (2012) discuss the perceived sameness concept, instead framing Parent to Parent support as a "source of funds of believable knowledge" (p. 96), a person who has or had a similar experience to what the person seeking support, they term this experiential empathy. This came through in the comments made by participants for example one said *"only someone who is or has walked in your shoes understands what you are going through"*, another said *"the connection with a parent with a similar disability is priceless – for a start you don't have to explain things which causes emotional roller coaster"*. This was further supported by the earlier question around emotional support with 36% (n=8) stating they accessed Parent to Parent to have help in feeling less alone, and 23% (n=5) for someone to listen and understand. Thirteen participants of the twenty (65%) who answered the question "I believe my

Support Parent matched worked because we are/were in similar situations” answered this as either agree or strongly agree, this lends further weight to perceived sameness being required for a match to be successful. Therefore, whilst Parent to Parent state it is not always possible to achieve a direct match, emphasis on achieving perceived sameness is vital for the relationship to occur between the help seeking parent and Support Parent.

### *Learning practical skills and useful information*

Parents approaching Parent to Parent are often also seeking practical information; for example, how do they care for their child and how do they access services for them (Santelli et al. 1996). Talking to the Support Parent means there is sharing of information, (e.g. what doctors parents found useful, how to access respite services, etc.). As discussed previously a large number of participants sought help from Parent to Parent in regards to information. When asked what the Support Parent did that was the most useful, 63% (n=12) of participants said they shared information about their experience and 16% (n=3) said they gave me productive information. A participant touched on this commenting *“It was a great resource in a time of not knowing.... They answered all my question(s) and I have become a strong person because of them...”*. Santelli and colleagues (1996) found that 46% of referred parents were seeking information support. This informational support was categorised into four key areas: receiving information about the disability, living with and caring for the child, finding and getting the best possible help for the family member with a disability, and information about community resources and services for the family. Singer et al. (2012) discuss the service system for those with disabilities and the stress involved with navigating this system. That parents and caregivers may face feelings of frustration and powerlessness when dealing the system and organisations. When parents are the main advocates for their children they may not know what to ask for, or struggle with meetings when they are overwhelmed and disempowered. The information service provided by Parent to Parent is therefore an essential service. The fact that parents are able to access this service at a time of their choosing (versus waiting for appointments with their doctor or paediatrician), with a broad range of information provided appears to be a strength of the Parent to Parent service.

### *Availability of Support*

In Ainbinder and colleagues (1998) qualitative study on the experiences of parents involved in Parent to Parent USA, common feedback from parents related to the availability of the support parent. Participants reported that just the knowledge that they could pick up the phone at any time to reach out for the help of the support parent was beneficial. This also made for ease of access, as parents may have free time that is outside of working hours when they can access their support parent but not other services. Due to the findings in Ainbinder et al. (1998) and that Parent to Parent NZ operates in a similar fashion, it was expected that the availability of the Support Parent may have been reflected in the comments. Perhaps surprisingly, no participants commented on being able to contact their Support Parent out of normal business hours.

### *Personal Growth/Mutuality of Support*

Part of the uniqueness of a peer support relationship is that both parties are going through the same thing (although they can be at different points in their journey). In the case of Parent to Parent there is the possibility of information and support being shared in both directions. Kerr and McIntosh (2000) discuss how many parents end up coming full circle, offering support to someone who was once in their shoes and that this process appears to be important to parents' adaptation to their child's condition. Out of the participants in the current study, two have stated in their comments that they have continued on to become a Support Parent themselves.

### *A refuge from Stigma and Misunderstanding*

Singer et al. (2012) discuss stigma, with regard to different cultures. Singer et al. (2012) discuss the common situation faced by many parents of a child with a disability, that when their child is behaving in what society deems an unacceptable manner that those around are quick to judge the parents. They go on to link this to isolation, and that it is this isolation and perception of being judged that is a crucial factor that leads to depression and anxiety in the parent population. Participants in the current study echoed this making comments such as "*p2p make you at the very least, listened to, supported, valued & not so isolated*" and "*...someone you can vent to when you need help and they are always non judgemental*". Therefore it is likely that when the parents are part of collective where they feel understood and accepted that this acts as a protective factor.



Whilst this is only alluded to in the comments left by the participants in the current study, it can be hypothesised that Parent to Parent NZ may provide this refuge.

#### *5.1.4 When the match or contact does not go well*

The similarities between the literature and comments made by the participants continue for when there are problems or barriers to a positive relationship forming. A number of factors have been identified in the literature that may negatively impact on the quality of the match. The most significant of these is when the sense of perceived sameness does not exist. Santelli et al. (1998) found that twenty per cent of their study sample did not find Parent to Parent helpful as they did not feel compatible with their match. One factor that may impact upon the likelihood of a successful match is when the children vary in their condition or presentation. Ainbinder et al. (1998) gives two examples of when this may happen; firstly is the downward comparison when the Support Parent's child has more significant challenges. When this difference is small it may create feelings of gratitude in the parent seeking support that they are not worse off, however, mostly the parent feels limited in what they can talk about. Secondly, is the upward comparison, when the Support Parent's child is doing much better than the parent seeking support. This can make the parent seeking support think their situation is more severe than they first thought, this came through in a comment made by a participant in the current study: *"Although our children have the same conditions my child's is much more severe so support has been limited in that aspect..."*. This can also occur when there is a significant difference in age, with another participant commenting *"...Her child was much much older and really she had been there and done it all. A match with a family closer in age may have been better and to have ongoing support"*. These comments are similar to those in Parent to Parent's social audit from 2005, with the comments in the audit emphasising that the match did not meet the needs of the person requesting it, for example when there was not a direct match or that they were at different stages of their journey.

Logistical barriers to building a positive relationship also occur, with both Santelli et al. (1998) and Ainbinder et al. (1998) discussing these. Ainbinder et al. (1998) breaks the logistical barriers down into four categories; parents' busy lives, long distances or difficulty with long distance calls, lost phone numbers and negligent follow up from the Support Parent. Comments made by the participants in the current study reflect that some of these logistical barriers still apply in the New Zealand context two decades on. One participant stated *"I would have liked more contact with her, I*

*never got her phone number, she was going to email me but I never received the email and because of that I have no way of continuing contact*". Other participants comments mirrored this theme of communication failures, *"We lost contact"* and *"Only had one contact with them. They did listen and offer advice but then never heard from them again"*. This suggests that there is a need for follow up by Parent to Parent NZ, and that the parent seeking support is being given information in the beginning on who to contact (e.g. their regional co-ordinator) if the match is not progressing.

Access also came through in the current study as a possible barrier, with two participants commenting on access. The first *"...one thing would be to always ensure that family events are held in environments that are easily accessible for children with mobility needs."* Parent to Parent runs family days that are to include all family members, however this participant has obviously found physically accessing these difficult with a child that has mobility needs. Another participant found access to sibling camps difficult stating *"It is a shame that an oplder (sic) child cannot go on siblings camp if they have minor health issue."* This suggests that while families are interested in attending family events there are possibly real or perceived barriers preventing them from doing so.

## **5.2 Strengths and Limitations**

### **5.2.1 Strengths**

There are a number of strengths of this study. This includes, the involvement of Parent to Parent NZ, the use of comments to provide richness to the data and the use of an online tool for completion of the survey.

At the time that this study was conceived and designed, it was hoped that the research would be beneficial to Parent to Parent NZ. No study on Parent to Parent NZ had been completed at the time and Parent to Parent's Social Audit (2005) had not been repeated in a decade. This study involved Parent to Parent NZ from the start and their input was used in both questionnaire design and implementation. It was hoped that the information gained from this study would support Parent to Parent NZ in their service provision and lend support to the argument that peer support is a useful tool to support parents of a child with a disability, special needs or chronic health condition.

The comments made by the participants in the current study provide a richness intended to supplement the numerical data. The combining of quantitative and qualitative information is

strength of this study that is shared by similar as studies such as Santelli et al. (1998) and Singer et al. (1999). The authors of these studies conducted a formal thematic analysis on their qualitative data, something that did not occur in this study – due to its design and time available for this thesis' completion. However, the comments made by the participants in the current study reflect the themes identified by participants in the other two studies.

Another strength of this study is the survey being accessible online. Both Dolnicar et al. (2009) and van Gelder, Bretveld and Roeleveld (2010) report that web-based questionnaires are less likely to be influenced by social desirability than other methods of data collection. Web based research is also considered to be cheaper than traditional paper and pencil questionnaires that require postage (Dolnicar et al, 2009; Heiervang & Goodman, 2011). Online surveys are generally a quicker and cheaper way of collecting data than phone or mail based surveys (Heiervang & Goodman, 2011).

### *5.2.2 Design Limitations*

There a number of limitations in this study, in the study design, the questionnaire design and implementation of the questionnaire. The study design and questionnaire design are discussed below with the questionnaire design discussing six key limitations. The implementation limitations are discussed in section 5.2.3.

The design required participants to consider the impact of a Support Parent in hindsight. Ideally this study would have taken a more experimental route with a control and test group similar to Singer et al. (1999) where participants in the test group completed questionnaires prior to being matched with a Support Parent and 3 months after their match. This could then be compared to the control group who would not be paired during this time. However, at the time of the study design concerns were expressed by Parent to Parent on the burden it would place on those in the study and the ethical implications of participants in the control group who would have to wait for support.

The questionnaire itself also had numerous limitations. Firstly, questions that sought important demographic information such as the gender of the participants; an essential element in the STROBE guidelines, were overlooked. This makes it difficult to establish whether the population is a representative sample – even if many more parents had participated.

Secondly, participants were able to select whether they were parenting alone or with a partner, however, the terms 'parenting alone' or 'with a partner' were not defined leaving this open for interpretation from the participants. This could mean that a participant who was not living with their partner would still potentially select parenting with a partner where another would view this as being alone. With the children being raised in single parent families, blended families and with grandparent involvement this is something that should have clearly been defined. When comparing the levels of support that the participants received, having this clearly defined is essential to ensure consistent responses for the quantitative analysis.

Thirdly, the lack of definitions may have contributed to further participant confusion resulting in contradictory responses in whether they were matched with a Support Parent. The inclusion criterion for the study was that the participant was matched with a Support Parent. There was a lack of definition around the term "matched". This could mean that a participant was only accepting that there was a match if they felt that they "got on" with their Support Parent, versus simply being put in contact with a Support Parent.

The forth limitation was questionnaire branching. Question 8 was inserted to ensure that the participant had been matched with a Support Parent, as this was necessary for the participant to be able to complete the questions in part 3 of the questionnaire. Due to the distance between these questions, questionnaire branching could not be used to prevent the problems occurring where participants stated they were not matched with a Support Parent but then continued on to answer the questions in part 3. In hindsight the layout of the questionnaire could have been altered to prevent this from occurring. This was noted during piloting, however it would have meant a complete re-ordering of the questionnaire; instead question 8 was inserted to act as a screening question as a next best option. Additionally "Not matched with a Support Parent" was added as an option on the Likert scale. The result of this coupled with participant interpretation of the questions meant that there were contradictory responses. The first was a participant who answered yes to being connected with a Support Parent, then when answering the questions in part 3, in all except one question, their response was – "not matched with a Support Parent". The second situation occurred with two participants stated in question 8 that they were not matched with a Support Parent, their responses to part 3 of the questionnaire were not collated due to this being exclusionary criteria. However they then continued with Part 3 of the questionnaire. Ideally those participants who stated they were not matched with a Support Parent would not have had access to Part 3 of the questionnaire, with "matched" having been clearly defined.

The fifth limitation was also discussed above in the strengths section. Participants had numerous opportunities to provide comments that were intended to provide richness to the data. However unlike the studies mentioned previously a full thematic analysis was unable to be performed due to the scope and timeframe of the study.

Finally, previous studies on Parent to Parent internationally have employed standardised and validated measures such as the Kansas Inventory of Parent Perceptions (KIPP) and the Parent Coping Efficacy Scale (PCES) (Santelli et al. 1998; Singer et al. 1999). However, the current study did not use standardised or validated scales (such as the aforementioned measures) because there were concerns around responder burden. It was also felt that a general questionnaire would provide the best way of gathering data without placing excessive demands on the participants. The questionnaire did not directly assess the sort of key psychological constructs that were assessed in the work of Singer et al. (1999) and Santelli et al. (1998). Indeed, a principle limitation of this study is that the questionnaire simply assessed and recorded the demographic details and opinions of the participants and did not measure their perceived levels of depression, isolation, coping, and empowerment. Therefore, it is not possible to infer the presence of these psychological constructs from the available data. Having such data available would enable researchers to infer the wellbeing and resilience of the parent. When this is coupled with pre and post intervention testing, this would provide quantitative data on the impact of the Support Parent match on the person seeking support.

### *5.2.3 Implementation Limitations*

The author of this study did not have access to any of the contact details for the service users of Parent to Parent NZ. Therefore recruitment for the study was undertaken with the support of Parent to Parent. The study was advertised on a number of mediums that were managed by Parent to Parent, as presented in Table 3.1 (pg. 42). However, in hindsight the likelihood of this reaching the entire population of Parent to Parent NZ service users was low. Whilst the current study attempted to use multiple mediums the likelihood of their effectiveness was low. Despite the vast numbers involved with Parent to Parent NZ, the number of people ‘following’ Parent to Parent NZ on their regional and national Facebook pages which was low, with some pages having only 35 ‘followers’. It is also possible that these people may not necessarily be Parent to Parent service users. This sampling frame was pursued as it meant accessing an existing tools that Parent to Parent were

using, it was hoped that it would be an efficient method of gathering data and that the advertisement might be shared or 'liked' by eligible participants creating a snowball sample. Khazaal and colleagues (2014) discussed the limitations around self-selection surveys that are advertised over online mediums. They report not only low participation rates but difficulties in ascertaining the extent of selection bias as information on those who did not complete the survey is unavailable. Khazaal et al. (2014) conclude that online self-selection surveys are particularly prone to issues with coverage and selection bias which can lead to concerns around the validity of the study and interpretation of findings. Promoting the current study outside the online forums was difficult. The 1,000 print copies of the magazine make up less than 10% of the 10,600 members, further, a proportion of these are supplied to organisations and supporters not just service users of Parent to Parent NZ. An opportunity was missed to promote the study with the Parent to Parent Annual General Meeting being held on the 18<sup>th</sup> October 2014, as this was prior to ethical approval for the study being granted by the University of Canterbury Human Ethics Committee.

Participation in the study was low. On further retrospective investigation this should not have been unexpected. Two health related studies recruiting their participants across multi-mediums such as email, enclosed with the target populations medical registration papers, mass advertisement, conference/lecture presentations and mail based postcards for participation in an online survey both received low response rates at 5% and 1.2% respectively (Turner et al. 2009; Askew et al. 2012). Initial estimations on the potential response rate to the study were made based off the responses to the 2005 Social Audit. For the 2005 Social Audit 167 questionnaires were sent out to families requesting support, with 37 being returned giving a response rate of 22%. Initial estimations of return were made using the number of people on the distribution list for the National Magazine alone. There are 1,000 National Magazines distributed and from the response rate of the 2005 Social Audit it was estimated that there would be approximately 220 responses. However, only 24 participants took part in this study, which presents a sample size far smaller than predicted by anyone involved in the study's design.

The recruitment strategy created a potential selection bias, with most of the advertisements of the study being electronic and the questionnaire itself being online, only those with internet access were able to be participants in the study. The Statistic NZ household use of information and communication technology survey (2012) states that four out of five New Zealand households had access to the internet. Of those households that did not have access to the internet over one-third stated that this was due to concerns around cost. Therefore the current study has potentially

excluded those in the lower socio-economic demographic. This responder bias was found to be a concern in Heiervang and Goodman (2011) where there was an overrepresentation of those in the higher socio-economic demographic due to their study being conducted online.

Tay (2013) conducted a similar themed study, on a similar population, (caregivers of a person with ASD), linked with an ASD provider (Autism NZ). Whilst the current study relied on existing mediums managed by Parent to Parent, Tay (2013) emailed members of Autism NZ directly with an invitation to participate in her study. In response to the email invite Tay (2013) recruited 184 participants. With participants likely to be similar, the fact that the recruitment method was the major difference between the current study and Tay (2013), recruitment via email should be a serious consideration to anyone wishing to complete research on this population.

### **5.3 Implications and Recommendations**

#### *Implications*

Although this study had a small response rate, there are still implications for Parent to Parent NZ. The majority of the participants in this study only had 0-1 contacts with their Support Parent. Whilst some still reported positive responses to the questions in Part 3, just as many had negative responses. With only 42% feeling that having a Support Parent match meant they have someone to talk to about their child's disability. Similar themes of lost/no phone numbers or match difficulties, means that the system around Support Parent's still has many of the issues identified in the 2005 Social Audit.

Parent to Parent NZ were highly involved from the start, however there were some difficulties with access to information, with staff turnover and no clearly identified person as a single point of contact. Whilst understanding that there are funding limitations having a single point of contact for those wishing to conduct research would have made this easier. Whilst Parent to Parent have a database of information this was unable to be accessed directly or easily via a staff member at Parent to Parent NZ.

## *Recommendations*

There are a number of recommendations that would improve future research, both in design and working with Parent to Parent NZ. Access to the Parent to Parent database would have a significant impact on the amount of time required for gathering information, further, this may enable analysis from existing information to supplement any further studies. With the small response rate in the current study this would have enabled the participants to be considered against those in the database to provide indications if they were a representative sample. Therefore, it is recommended that those wishing to complete research on Parent to Parent NZ have the ability to readably access information from Parent to Parent directly. While not necessarily feasible due to staffing, the study would have been further aided by having a key contact person at Parent to Parent who had the clearance to access all information and a firm knowledge of the workings of Parent to Parent NZ. It would be hugely beneficial to have an identified person who would act as a liaison for any future research.

A different methodological approach would also be encouraged for future research in this area. A study utilising existing scales and questionnaires that have been validated is highly recommended. This would enable greater clarity of questions and could provide sound information on such psychological constructs as coping. The method of recruitment in future studies should also be considered, where possible having the ability to promote the study in person at forums and meetings may build rapport creating a higher response rate. Recruitment via social media proved to be unsuccessful. Sending email invitations with a link to SurveyMonkey® may yield higher responses. However, Parent to Parent NZ had higher success with their recruitment in the Social Audit (2005), and therefore a paper and pencil study sent out by post should not be disregarded.

### **5.4 Further research**

This study failed to answer the questions it set out to. While international research supported being matched with a Support Parent had a positive impact of those seeking support, this has not been established within the New Zealand context. Future research into Parent to Parent NZ or other organisations providing similar services, will require an epidemiologically more robust sample gathered through diverse recruitment techniques to achieve definitive results. While not used in the current study, incentivising responses with a prize draw or koha may increase response rates. Where possible the use of a control and test group should also be considered with psychometrically tested



and standardised instruments. The previously used measures mentioned in this study would provide quantitative data on the impact a Support Parent has on the feelings of isolation, depression of a parent seeking support and whether there is an emergence of positive feelings of coping and empowerment. This study did show participants willingness to provide comment when asked, and therefore any future research should include the qualitative component to provide richness to the data.

While SurveyMonkey® had initially seemed like a useful and appropriate tool, it did have limitations in terms of needing to pay for the service, and only being able to access the final results on SurveyMonkey® whilst paying for them. It was also initially confusing and labour intensive for loading the questionnaire requiring support from an experienced user of SurveyMonkey®. Those looking at completing research in this area should consider all available tools and mediums. Qualtrics is reported to be a useful alternative to SurveyMonkey® in academic research (Benton, Pappas, & Pappas, 2011). Currently Canterbury University has a licence to use Qualtrics which is supported by online training and a support team.

## **5.5 Conclusion**

Parent to Parent NZ provides support to those parenting a child with a disability, special needs or chronic health condition. This is a role that is often demanding and can place significant burden on the parent. As these conditions are not readily 'fixable' in accordance with the traditional medical model of physical health a more holistic service is required to support those parenting children with high support needs. The peer support relationship of a Support Parent has anecdotally and internationally shown to be beneficial to a parent seeking support. The current study sought to answer three research questions 1) who was accessing Parent to Parent, 2) to establish why the participants are accessing Parent to Parent and what services are they accessing and 3) to establish whether those accessing the services of a Support Parent for this a useful experience. Whilst there were numerous limitations in to the current study, most notably of which was the extremely small sample size, comments made by participants are encouraging. A number of participants reported an overall positive impact of having being matched with a Support Parent. Accordingly, there is scope for further research on how beneficial Parent to Parent NZ's peer-support service is to those who seek support from the organisation. Furthermore, it may be valuable to consider applying a scientific method to the survey process to fully determine how the support parent service alters the participants' perceived levels of depression, isolation, coping and empowerment.

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- Jury C. Personal correspondence. Support Parent and Information Coordinator, Parent to Parent NZ; 01 December 2015.
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Ritchie D. Personal correspondence. Administration and Finance Manager, Parent to Parent Ltd: Scotland; 06 June 2016.

Rollason K. Personal correspondence. Parent Co-ordinator, Parent to Parent Queensland: Australia; 11 December 2015

Russell D. Personal correspondence. Professor, Department of Human Development & Family Studies, Iowa State University; 22 February 2014

Smith R. Personal correspondence. General Manager, Parent to Parent NZ; 27 February 2016.

Summers J. Personal correspondence. Associate Director, Beach Centre on Disability. University of Kansas; 22 February 2014

Wilkinson A. Personal correspondence. Chief Executive Officer, Parent to Parent NZ; 15 May 2016.

Wilkinson A. Personal correspondence. Chief Executive Officer, Parent to Parent NZ; 30 May 2016

## Appendix A



### HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen  
Email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)

Ref: HEC 2014/84

2 February 2015

Jessamy Green  
School of Health Sciences  
UNIVERSITY OF CANTERBURY

Dear Jessamy

The Human Ethics Committee advises that your research proposal "Effectiveness of parent to parent support in the New Zealand population" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 27 January 2015.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L. MacDonald'.

Lindsey MacDonald  
*Chair*  
*University of Canterbury Human Ethics Committee*



## Appendix B

The list below was retrieved from <http://www.kidshealth.org.nz/health-and-disability-support-z> on 7th November 2015

### A

- Addison's Network (New Zealand)
- ADHD Online Support Group (New Zealand)
- Allergy New Zealand
- Anxiety Disorders (see Phobic Trust of New Zealand)
- Arthritis New Zealand (see Children with Arthritis)
- Asperger Syndrome (see Autism New Zealand or Cloud 9 Children's Foundation New Zealand or Jen Birch's Personal Asperger Syndrome Web Site)
- Asthma Foundation of New Zealand
- Asthma New Zealand
- Autistic Spectrum Disorder (see Autism New Zealand or Cloud 9 Children's Foundation New Zealand or Jen Birch's Personal Asperger Syndrome Web Site)
- Autism New Zealand

### B

- Barnardos New Zealand - An organisation providing services to children and families throughout New Zealand
- Bedwetting (see KEEA - Kiwi Enuresis Encopresis Association at New Zealand Continence Association)
- Blindness (see Royal New Zealand Foundation for the Blind)
- Bone Marrow Transplant Children (see IDFNZ: Immune Deficiencies Foundation of New Zealand)
- Brain Injury Association New Zealand
- Breastfeeding (see La Leche League New Zealand and NZ Breastfeeding Authority)

### C

- Cancer (see Child Cancer Foundation or CanTeen)
- CanTeen - Supports young people aged 13-24 years living with cancer or a life-threatening blood disorder and their teenage siblings
- Carers New Zealand - Grassworks network for New Zealanders who care for sick, injured and disabled family members at home
- CCS Disability Action
- Cerebral Palsy (see Carlson School for Cerebral Palsy or Cerebral Palsy Society of New Zealand)
- Child Cancer Foundation
- Cleft New Zealand
- Cloud 9 Children's Foundation New Zealand - Asperger Syndrome support and information organisation
- Cochlear Implants (see the National Foundation for the Deaf)
- Coeliac Society of New Zealand
- Continence Problems (see New Zealand Continence Association) - Includes section on Continence information for children (including bedwetting and daytime wetting)
- Counselling services: Free, national, professional telephone counselling service for all five to 18 year olds that offers anonymous, confidential and child-centred counselling seven days a week between noon and midnight (see What's Up). A web site designed to complement National 0800 Kidsline (0800 543 754), a 24 hour telephone help line for school-aged

children (five to 18 years) (see KidsLine). A web site which complements a free telephone counselling service for young people (0800 376 633) (see Youthline)

- Crohn's & Colitis New Zealand
- Cystic Fibrosis Association of New Zealand

## D

- DEBRA New Zealand - The DEBRA New Zealand Trust is an organization dedicated to the improvement in the quality of life for all people with epidermolysis bullosa and their families. Epidermolysis bullosa is the name of a group of genetic disorders causing blistering and shearing of the skin from even the gentlest friction, often from everyday activities
- Diabetes New Zealand
- Disabilities - General (see Enable New Zealand or Halberg Trust or New Zealand Riding for the Disabled Association Inc or Weka)
- Disabilities - Intellectual (see Halberg Trust or IHC New Zealand or New Zealand Riding for the Disabled Association Inc or Rescare New Zealand or Weka)
- Disabilities - Physical (see Enable New Zealand or Halberg Trust or CCS Disability Action or New Zealand Riding for the Disabled Association Inc or Weka)
- Disability Support Services (see Enable New Zealand or Weka)
- Down Syndrome (see New Zealand Down Syndrome Association)
- Dwarfism (see Little People of New Zealand)
- Dyslexia (see SPELD New Zealand - Specific Learning Disabilities Federation)
- Dyspraxia (see SPELD New Zealand - Specific Learning Disabilities Federation)

## E

- EB (Epidermolysis Bullosa) (see DEBRA New Zealand) - The DEBRA New Zealand Trust is an organization dedicated to the improvement in the quality of life for all people with epidermolysis bullosa and their families. Epidermolysis bullosa is the name of a group of genetic disorders causing blistering and shearing of the skin from even the gentlest friction, often from everyday activities
- Eczema (see Itchy Kids)
- Ehlers-Danlos Foundation of New Zealand
- Enable New Zealand - Enable New Zealand is a multi-service organisation working to assist disabled people and their families/whanau, employers, health professionals and disability support organisations. Some of Enable's services are available nationwide, while other services are provided regionally
- Encopresis (see KEEA - Kiwi Enuresis Encopresis Association at New Zealand Continence Association)
- Enuresis (see KEEA - Kiwi Enuresis Encopresis Association at New Zealand Continence Association)
- Epidermolysis Bullosa (EB) (see DebRA New Zealand) - The DEBRA New Zealand Trust is an organization dedicated to the improvement in the quality of life for all people with epidermolysis bullosa and their families. Epidermolysis bullosa is the name of a group of genetic disorders causing blistering and shearing of the skin from even the gentlest friction, often from everyday activities
- Epilepsy New Zealand

## G

- General Disabilities (see Enable New Zealand or New Zealand Riding for the Disabled Association Inc or Weka)
- Grandparents Raising Grandchildren
- Grief (see Skylight or SANDS New Zealand (Stillborn and Neonatal Death Support) or SAFDA (Support after Foetal Diagnosis of Abnormality) or Twin and Multiple Birth Loss New Zealand)

## H

- Haemochromatosis - information and support and a dedicated haemochromatosis line is now provided at the Leukaemia and Blood Cancer NZ website
- Haemophilia New Zealand
- Halberg Trust - Supports children with a disability to be involved in active leisure or recreation of their choice, alongside their peers in an inclusive environment
- @Heart (previously Heart Children New Zealand)

## I

- IDFNZ (Immune Deficiencies Foundation of New Zealand) - IDFNZ is a non-profit organisation dedicated to supporting children, teenagers and adults with diagnosed PID (Primary Immune Deficiency) disorders. The Kids Foundation is the welfare arm of IDFNZ and is responsible for caring for suspected or diagnosed PID children, teenagers and their immediate families, as well as BMT (bone marrow transplant) children
- IHC New Zealand New Zealand's largest provider of services to people with intellectual disabilities and their families
- Immune Deficiencies (see IDFNZ: Immune Deficiencies Foundation of New Zealand)
- Intellectual Disabilities (see IHC New Zealand or New Zealand Riding for the Disabled Association Inc or Rescare New Zealand or Weka)
- Itchy Kids - Support group for parents of children with eczema

## J

- Jen Birch's Personal Asperger Syndrome Web Site

## K

- K.E.E.A. Kiwi Enuresis Encopresis Association supports families who have children with wetting and soiling problems
- Kidney disorders (see Kidney Kids and Kidney Health New Zealand)
- Kidney Health New Zealand
- Kidney Kids
- Kids Foundation (see IDFNZ: Immune Deficiencies Foundation of New Zealand)
- KidsLine - A web site designed to complement National 0800 Kidsline (0800 543 754), a 24 hour telephone help line for children under 13 years of age

## L

- La Leche League New Zealand - For breastfeeding support and education
- Learning Disabilities (see SPELD New Zealand - Specific Learning Disabilities Federation)
- Leukaemia and Blood Foundation of New Zealand
- Little People of New Zealand
- Lupus (see Arthritis New Zealand or Lupus Trust of New Zealand)
- Lupus Trust of New Zealand
- Lysosomal Diseases New Zealand

## M

- Mental Health (see Headspace or Mental Health Foundation of New Zealand)
- Mental Health Foundation of New Zealand
- Muscular Dystrophy Association of New Zealand

## N

- New Zealand Continence Association
- New Zealand Down Syndrome Association
- New Zealand Organisation for Rare Disorders
- New Zealand Riding for the Disabled Association Inc - Offers therapy and rehabilitation; education, behaviour modification and social contact; horse riding for sport and recreation for people with disabilities

## P

- Parent and Family Resource Centre - An umbrella organisation for a network of support groups and parents in Auckland, New Zealand. The main aim of the centre is to create support and skill development opportunities that can empower parents of children with special needs. The organisation is parent driven, parent focused and open to all in the disability community
- Parent to Parent - Parent to Parent New Zealand is a national organisation working with families and children affected by disabilities, health impairments, rare syndromes, and special needs. Parent to Parent currently has contacts available for 638 different disabilities and information relating to over 1800 disorders. Support groups both in New Zealand and overseas are listed for over 3500 conditions
- Perthes Support Group (Perthes disease). Contact details for the Perthes support group are listed in the NZORD (New Zealand Organisation for Rare Disorders) website support groups directory (check under "P")
- Phobias (see Phobic Trust of New Zealand or Mental Health Foundation of New Zealand)
- Physical Disabilities (see Enable New Zealand or CCS Disability Action or New Zealand Riding for the Disabled Association Inc or Weka)
- Prader-Willi Syndrome Association of New Zealand
- Primary Immune Deficiency Disorders (see IDFNZ: Immune Deficiencies Foundation of New Zealand)

## R

- Rare Disorders (see New Zealand Organisation for Rare Disorders)
- Rescare New Zealand
- Royal New Zealand Foundation for the Blind

## S

- SAFDA - Support after Foetal Diagnosis of Abnormality
- SANDS New Zealand - Stillborn and Neonatal Death Support
- Schizophrenia Fellowship NZ
- Skylight - Skylight is a national organisation working to support children, young people and their families who have been affected by change, loss and grief
- Soiling (see KEEA - Kiwi Enuresis Encopresis Association or New Zealand Continence Association)
- Speakeasy - New Zealand Speak Easy Association Inc - A support group for people who stutter
- SPELD New Zealand - Specific Learning Disabilities Federation
- Spina Bifida Association New Zealand
- Stillborn and Neonatal Death Support (see SANDS New Zealand)
- Stuttering (see Speakeasy - New Zealand Speak Easy Association Inc)

## T

- Twin and Multiple Birth Loss NZ

## W

- Weka New Zealand's disability information web site
- What's Up - Free, national, professional telephone counselling service for all 5 to 18 year olds that offers anonymous, confidential and child-centred counselling 7 days a week between noon and midnight

## Y

- Youthline - A web site which complements the free telephone counselling service for young people (0800 376 633)

## **Appendix C**

### **Parent to Parent**

#### **History**

Parent to Parent was established in 1988 following a conference held in Ninewells Hospital in Dundee, Scotland for parents of young children with disabilities. The conference brought together parents, health professionals, social workers and education staff to look at the support available for parents in Tayside (Angus, Dundee and Perth & Kinross). It became clear that there was a gap in the early years of a child's life, between birth and the child starting to attend school. Parents said they felt isolated and worried about their child's future, uncertain what to expect and what to ask for. Once they started to meet other parents at their child's school they felt much more supported, knowledgeable and empowered.

Some of the parents who attended the conference set up a steering group with representatives from the statutory agencies to establish an organisation that would meet this need. They recruited and trained volunteer parents, all parents of children with a disability, to provide emotional support to new parents, be a link to support groups and give information about appropriate services in the local area. The service covered Angus, Dundee and Perth & Kinross.

Volunteers continued to be the main provider of support until 2000 when it was decided to employ a support worker who could provide more intensive support to those families who needed it. Since then the organisation has grown to provide support to any parents of a child with an additional need living in Tayside. Eleven support workers and three young persons' support workers now provide the bulk of the support to approximately 800 families per year. Volunteers are still used to support parents when appropriate.

#### **Hospital support**

One of the projects within Parent to Parent is support to parents of pre-term, ill and disabled babies who start life in the Neonatal Unit in Ninewells Hospital. The majority of parents do not expect their baby to need this intensive care and they can feel overwhelmed, anxious, frightened and uncertain of the future. One of Parent to Parent's support workers visits the Neonatal Unit several times per week and spends time with parents giving reassurance, answering questions and helping them to speak to medical staff about their concerns. She provides loss and bereavement support to parents who struggle to come to terms with their baby's illness or disability or whose baby sadly dies. Loss and bereavement support is also available to other family members and will continue for as long as the family needs it.

The worker also visits the special infant clinic and supports parents while they wait for their baby's appointment with the Doctor. This can be an anxious and upsetting time for parents as they may

receive the results of tests which could be bad news. The worker will care for the baby's siblings in the hospital play-room should the parents need some quiet time with the Doctor and will spend time with them after the appointment.

The support worker visits the paediatric wards when one of her family's children has been admitted. It can be a lonely and worrying time for parents whose child is ill and the worker will sit and chat to them, take them out of the ward for a coffee break or stay with their child if they are reluctant to leave him so they can get a break. She liaises between parents and the nursing and medical staff when parents are unhappy or confused about an aspect of their child's care and helps to relieve some of the tensions.

The worker continues to provide support once the baby or child has left hospital. She visits the family home to chat to parents and provides information about appropriate nurseries, support groups, benefits, equipment and can link them to a volunteer parent who understands their situation.

### **One to one Support**

The bulk of our work is one to one support for parents. Their worker will go to parent's home and spend time building a relationship with them and gaining their confidence. She is then able to offer support, whether emotional or practical. A lot of parents benefit from having someone who is able to listen to them without judging and being emotionally involved.

### **Advocacy**

Many parents have to attend a lot of appointments and meetings for their child. Some find it daunting to walk into a room with many professionals there and are reluctant to speak about their concerns or voice their views. The support workers will go with them and help them to prepare for the meeting. They will speak for them if required and encourage them to ask questions. Having someone with them can make a huge difference and enables parents to discuss the issues affecting their child with more confidence.

### **Behaviour Management**

An increasing number of referrals are made for help to manage challenging behaviour. Conditions such as Autistic Spectrum Disorder and Attention Deficit Hyperactivity Disorder can lead to difficult behaviours. These include aggression, poor sleeping patterns, refusal to eat the majority of foods, inability to comply with social norms and repetitive behaviour such as head banging. Our team of support workers can help parents deal with these issues and find ways to cope with them. They run three day behaviour management courses and work through a parenting programme over several months with parents who are referred for more intensive support.

### **Group support**

Many parents benefit from meeting others who have experienced a similar situation and several of the support workers have established groups where parents can meet for a chat and mutual support. These run across Tayside and are well supported. Some focus on support for parents of children with challenging behaviour, some for parents of disabled children, young children with disabilities, children with Autistic Spectrum Disorder and bereaved parents. There are currently 14 groups running across Tayside.

### **Volunteers**

When the organisation first started it relied heavily on volunteers, all parents of children with additional needs. They were trained to give emotional support and some brief information about other organisations that could be of benefit to the family. We now rely less heavily on volunteers as the number of referrals is too great and the needs of the families require help from people with more skills and experience. We now use volunteers to support families who have already had support from their support worker but no longer need intensive support. When the support worker identifies that they would benefit from speaking to another parent of a child with similar difficulties they pass them onto one of our volunteers. On many occasions firm friendships are formed which is of benefit to both parents.

## Appendix D

<b>Referrals 1/1/15 – 1/1/16</b>	
3D	1
AA 0800 number	2
AA Brochure	11
AA Info Cord	18
AA Network Meeting	44
AA Website	227
Alt Aut Conference 2013	1
Alt Aut Conference 2015	2
Alt Aut newsletter/journal	2
ASD Coord	59
ASD Introduction pack	1
Autism NZ	20
Brain Injury Trust	5
CAMHS	11
CCS	26
Child Development Centre	113
Citizens Advice Bureau	3
Cloud 9	1
Counsellor	7
DHB	25
Disability Info Service	21
Disability Support Link	13
Doctor	6
Down Syndrome Group	4
Dyspraxia Support Group	5
Early Childhood Centre	2
Facebook	28
Family member	13
Family Network Inc	5
Friend	57
GP Conference	1
Group Special Education	2
Health & Disability Commissioner	1
Health Expo	17
Hospital	14
Hospital Nurse	2
Hospital Paediatrician	5
IDEA Services	7
IEP Seminar	3



Internet	28
Kari Centre	1
Kindergarden	2
LIFE Unlimited	3
Mental Health	4
Midwife	1
Ministry of Education	5
NASC Agency	7
National Office Staff	1
Newspaper Advert	1
Other	41
P2P Awareness Week	1
P2P brochure	5
P2P Forum	1
P2P Website	38
Paediatrician	10
Parent Panel	1
Parents as First Teachers (PAFT)	1
Paula Gardner	1
Plunket Nurse	7
PRISM	1
Psychologist	4
Regional Coordinator P2P	58
Richmond Trust	3
Rural GP Conference	107
School	7
Smile Dial NZ Inc.	1
Social Worker	9
Strengthening Families	3
Support Group	8
Support Parent	10
Supporting Families	1
Tanya Breen	7
Te Whanau Kotahi	17
Therapist	1
Used Service Before	1
Visiting Therapist	1
Word of mouth	84
Blank	448
<b>TOTAL</b>	<b>1715</b>

## Appendix E

### Part 1 - demographics

- 1) *Are you the...*  
Biological Parent?  
Adoptive or Foster Parent?  
Guardian?  
Grandparent?  
Other? \_\_\_\_\_
- 2) *Are you parenting*  
Alone?  
With a partner?
- 3) *Do you receive additional support, such as emotional or practical, from any of the following?*  
*(you may tick as many as appropriate)*  
Immediate family  
Wider whanau (extended family group)  
Other support groups  
Other \_\_\_\_\_  
No other support
- 4) *Which ethnic group do you belong to? Mark the space or spaces which apply to you:*  
NZ European  
Māori  
Samoan  
Cook Island Māori  
Tongan  
Niuean  
Chinese  
Indian  
Other such as Dutch, Japanese, Tokelauan. Please state: \_\_\_\_\_
- 5) *What region do you live in?*  
Northland  
Auckland  
Waikato  
Coastal Bay of Plenty  
Central Lakes  
Manawatu  
Wellington  
Nelson  
Canterbury  
Otago  
Southland

- 6) *What type of disability, health condition or special needs does your child have? (please state):* \_\_\_\_\_
- 7) *What level of disability, health condition or special needs do **you** feel your child has?*  
 Mild  
 Moderate  
 High  
 Very high
- 8) *Have you been connected with a Support Parent*  
 Yes  
 No
- 9) *Having been connected with a Support Parent - how many contacts have you had with your parent match?*  
 0-1  
 2-4  
 5+  
 N/A
- 10) *Having been connected with a Support Parent do you have an ongoing relationship with your Support Parent?*  
 Yes  
 No  
 N/A
- 11) *What was the method of communication you used that was the most meaningful?*  
 Phone  
 Face to Face  
 Video Conferencing at Parent to Parent  
 Online networking: email (Skype, facebook etc)  
 Other \_\_\_\_\_  
 N/A

## Part 2

- 12) *What is the MAIN reason you contacted Parent to Parent?*  
 Information  
 Emotional support  
 In order to join a support group  
 Support for sibling or other family of the child  
 For advice of a specific issue/problem  
 To be paired with a support parent  
 Other \_\_\_\_\_
- 13) *If you contacted Parent to Parent on only one occasion what best describes the reason for only one contact?*  
 I got the information I needed  
 I didn't get the information I needed  
 I wanted to know what Parent to Parent was about

I was referred to another agency  
I got the support I needed  
I got connected with a support parent  
Other \_\_\_\_\_  
N/A

14) *If you contacted Parent to Parent for information please tick the box that best applies:*  
Information about your child's disability/health condition/special needs  
Information on an issue relating to your child's disability/health condition/special needs  
Information on a care aspect  
Information on community resources  
Information on other services  
Financial information or advice about financial options (e.g. disability allowance)  
Information on respite care  
Other \_\_\_\_\_  
N/A

15) *If you contacted Parent to Parent for emotional support which of these best describes the key reason?*  
Someone to listen and understand  
Hope for the future  
Help in feeling less alone  
Ways to deal with stress  
Dealing with the diagnosis of a disability/health condition/special needs  
Problem solving support  
Other \_\_\_\_\_  
N/A

16) *Of the services provided by Parent to Parent, please tick the ones that you have found most useful:*  
Information on the disability/health condition/special needs  
Information on supports and services and how to access these  
Sibling support programmes –children's programme (SibSupportN.Z.)  
Adult sibling workshop (2<sup>nd</sup> Generation)  
Training and workshops  
Coffee and support group get-togethers for parents  
Family camps and activities  
Being connected with Support Parent  
Other \_\_\_\_\_

17) *If you were to use Parent to Parent again in the future, which services offered by Parent to Parent would you most likely use?*  
Information on the disability/health condition/special needs  
Information on supports and services and how to access these  
Sibling support programmes –children's programme (SibSupportN.Z.)  
Adult sibling workshop (2<sup>nd</sup> Generation)  
Training and workshops  
Coffee and support group get-togethers for parents  
Family camps and activities  
Being connected with Support Parent

18) If you were to use Parent to Parent again, would there be any additional services that would be useful to you?

Yes

No

19) If yes, please state:

20) Would you recommend Parent to Parent to another parent?

Yes

No

21) Please explain your answer:

22) Is there anything you would like to comment on regarding the services provided by Parent to Parent?

### Part 3

23) If you have been put in touch with a Support Parent (matched) please complete the following:

(i) My Support Parent match worked for me

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A

(ii) I believe my Support Parent match worked because we are/were in similar situations

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A

(iii) Because of my match I feel like I have someone to talk to about my child's disability/ health condition/special needs

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A

(iv) I felt like I could say anything to my Support Parent

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A

(v) Since my Support Parent match I feel empowered to get the resources or services my child needs

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A

(vi) *Since my Support Parent match I feel that I can better cope with situations around my child's disability/health condition/special needs*

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A

(vii) *Since my Support Parent match I feel that I can better advocate for my child*

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A

(viii) *My Support Parent match has given me the confidence to make my own contacts/supports and link with others in a similar situation to me*

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A

24) *What was it that the Support Parent did that was the most useful?*

They listened

Gave productive information

Shared from their experience

Gave advice

Other: \_\_\_\_\_

25) *Do you have any comments surrounding your match with your Support Parent?*

26) *That is the end of the questionnaire. Please tick here to consent to your comments being used / quoted in the final report.*

27) *If you wish to be kept informed about the project, please provide your email address. Your email address will be added to a discrete group for the purpose of communicating progress only.*

28) *Would you like a copy of the completed thesis sent to the email address you have supplied?*

## Appendix F

### Research Assistant Confidentiality Agreement

This study, *Self reported impact of parent peer support to parents of a child with a disability / special needs / chronic health condition*, is being undertaken by Jessamy Green at the University of Canterbury, supervised by Professor Garry Hornby and Professor Philip Schluter.

The study has 3 objectives:

1. To establish who is using the services Parent to Parent New Zealand;
2. To establish what services offered by Parent to Parent New Zealand are being used;
3. To examine the impact informal peer support has on parents who have a child with a disability / special needs / chronic health condition.

Data from this study will be used for the completion of a Masters thesis, Masters of Health Science.

I, Amanda Duncan, agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g. disks, tapes, transcripts) with anyone other than the Principal Investigator(s);
2. Keep all research information in any form or format secure while it is in my possession;
3. Return all research information in any form or format to the Principal Investigator(s) when I have completed the research tasks;
4. After consulting with the Principal Investigator(s), erase or destroy all research information in any form or format regarding this research project that is not returnable to the Principal Investigator(s) (e.g. information stored on computer hard drive).

Research Assistant:

AMANDA DUNCAN		16 Jan. 2015
(print name)	(signature)	(date)

Principal Investigator:

_____	_____	_____
(print name)	(signature)	(date)

If you have any questions or concerns about this study, please contact:  
Professor Garry Hornby  
garry.hornby@canterbury.ac.nz

This study has been reviewed and approved by the Human Ethics Committee at Canterbury University. For questions regarding participants rights and ethical conduct of research, contact the HEC Chair, Lindsey MacDonald, human-ethics@canterbury.ac.nz or 0274 482 289

## **Appendix G**

Hi my name is Jessamy Green and I am currently completing a Masters in Health Science through Canterbury University. I have worked in the Health and Disability Sector for the last 10 years, currently I work with people with intellectual disabilities. For the final part of my Masters I am undertaking research into the impact made on parents by having a trained Support Parent through Parent to Parent. I am hoping that by completing research in this area it will show the importance of having services like Parent to Parent that provide peer support and information. To complete this I am asking for any parents that have been matched with a trained Support Parent to go to <https://www.surveymonkey.com/s/SupportParentSurvey> and complete a brief 10-15 minute survey, all responses are completely anonymous and this research is being completed independent of Parent to Parent. This link will be live until 21 June 2015, more information will be given by following the link or you can contact me on [jessamy.green@pg.canterbury.ac.nz](mailto:jessamy.green@pg.canterbury.ac.nz) if you have any questions. Thank you for your time.



## Appendix H

School of Health Sciences – Canterbury University  
jessamy.green@pg.canterbury.ac.nz  
1 September 2014

### **Effectiveness of Parent to Parent support in the New Zealand population**

#### **Information Sheet for participants who have used Parent to Parent Services**

My name is Jessamy Green and I am a Masters of Health Sciences student with Canterbury University.

- This research aims to look at the effectiveness of Parent to Parent in New Zealand, both in the services it provides and in the impact of those services on parents.
- The questionnaire is in three parts:
  - firstly, demographic information – for example what region you are in, what support you have around you and the disability/chronic illness/special needs your child has;
  - secondly, the services used and why those services were accessed;
  - the third part looks at the impact this has had on parents, for example, if feelings of empowerment have occurred after being put in contact with a Support Parent.
- There is the option for you to make general comments at the end of the questionnaire, please be aware these maybe quoted in the final report.
- At no point will the questionnaire ask you for any identifying information.
- Your involvement in this project will be through the completion of the questionnaire. This will be done online through Survey Monkey. There are 29 questions in total, these include tick box answers or “on a scale of 1-5”. This questionnaire should take you approximately 10-15 minutes to complete.
- At the completion of survey if you wish to be kept informed about the project, you will have the opportunity to provide an email address which will be added to a discrete group for the use of communicating progress only. A tick box will also appear at the end of the survey to have a copy of the completed thesis sent to the supplied email address. The expected completion of the thesis is December 2015.
- Participation is voluntary and you have the right to withdraw at any stage without obligation or penalty. If you decide to withdraw mid-survey, simply close the browser. Once the questionnaire has been submitted, due to the anonymity of the questionnaire, I will not know your answers from the other participants, therefore, I am unable to withdraw your responses once they have been submitted.
- If at any stage during or after the completion of the survey you feel any emotional distress,
- The results of the project may be published; no data will be gathered that will identify you. Your name or any contact details will not be asked of you at any point; you may, however, choose to be kept informed of the project through email. This information will not be released to anyone and will be stored appropriately and securely.
- As this questionnaire is completely anonymous, your consent is assumed by your voluntary participation and completion of the questions.
- All data will be stored on password protected computers. Post completion of the thesis in 2016 all data will be saved for five (5) years and then destroyed.

- Parent to Parent will only receive the final report that is available to anyone on request. At no point will any of your information, or your participation, be noted by Parent to Parent as this research is independent of them.
- A thesis is a public document and will be available through the University of Canterbury Library.
- The project is being carried out as a requirement for the Masters in Health Sciences by Jessamy Green under the supervision of Professor Garry Hornby, who can be contacted at [garry.hornby@canterbury.ac.nz](mailto:garry.hornby@canterbury.ac.nz). He will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch ([human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)).